



**Illness representations, coping, illness outcomes, and support needs of  
people with cancer and anxiety/depression**

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BPsych(Hons)

Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

(Psychology) in the Faculty of Health, School of Medicine

University of Tasmania, March, 2017

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## **Abstract**

Cancer and anxiety/depression commonly occur as co-morbid conditions, leading to poorer health and illness outcomes as well as reduced quality of life in those affected. However, currently too little is understood about the impact of this combination of illnesses. In order to determine how people with cancer and anxiety/depression can be best supported to improve health and illness outcomes, as well as to identify what supports and services they may need, it is important to understand the psychological processes underlying coping behaviours and illness outcomes for people with each illness separately and for those with combinations of cancer and anxiety/depression. This thesis therefore aimed to firstly examine how the illness representations of people with cancer (Study 1) and of people with depression (Study 2) separately influenced coping responses and illness outcomes. Secondly, this thesis aimed to examine how having a combination of cancer and anxiety/depression would influence illness representations, coping and self-management behaviours, and support needs (Study 3), as well as how such support needs might differ across cancer patients with varying histories of anxiety/depression (Study 4).

The leading psychological model of self-regulation in the face of illness is Leventhal's Common Sense Model of health and illness (CSM), which assumes that people form and access subjective representations of their illness based on common-sense assumptions. These idiosyncratic representations then guide individual coping attempts and processes. The CSM's illness representation dimensions have been found to be reliably associated with coping and outcomes for a variety of chronic illnesses. However, although several studies have investigated these relationships in people with cancer, no systematic review and meta-analysis to summarise these associations had yet been conducted. The same lack of a systematic overview of the evidence was also found for anxiety/depression. Based on these existing gaps in the literature, two separate systematic reviews and meta-

analyses were conducted to determine the strength and direction of the relationships between illness representations and coping behaviours as well as illness outcomes in people with cancer (Study 1) and in people with depression (Study 2). The systematic literature search for Study 1 located 54 studies, with 38 providing sufficient data for meta-analysis and 16 narratively reviewed, while the literature search for Study 2 located 19 studies, with 10 included in the meta-analysis and nine narratively reviewed. During the systematic review process for Study 2 only one study examining illness representations in people with anxiety was located, making a review of people with anxiety impossible. Both reviews found substantial relationships between illness representations and coping as well as illness outcomes, with findings suggesting that for people with cancer and for people with depression, higher identity (more symptoms), a more chronic and cyclical timeline, more severe consequences, less personal and treatment control, less illness coherence, and stronger emotional representations were associated with maladaptive coping strategies and increased psychological distress.

This evidence base served as a starting point for the second set of studies in this thesis. As cancer and anxiety/depression commonly co-occur, whether and how the CSMs illness representation dimensions were associated with coping and outcomes in people with multimorbid cancer and anxiety/depression was explored. As no research had yet investigated the multimorbid representations of people with cancer and anxiety/depression specifically, Study 3 included 21 semi-structured interviews and used theoretical thematic analysis to examine the structure and content of individual's representations of co-morbid cancer and anxiety/depression, as well as how these related to coping and self-management. This study found that participants most often perceived their cancer and anxiety/depression as related, with these interactions often considered causal (albeit with heterogeneity in which illness caused the other). In terms of illness representations, personal control and illness coherence

emerged as important determinants of illness behaviour, with these representations shown to have both positive and negative influences on coping and self-management. These results suggested that better understanding of multimorbid representations by health professionals have the potential to lead to improved self-management strategies and health care interactions for people with cancer and anxiety/depression. As Study 3 began to identify differing support needs across people with cancer and anxiety/depression, Study 4 used inductive thematic analysis on data obtained from 21 semi-structured interviews to examine how the existing needs and supports of this population differed based on experiences of varied histories of anxiety/depression (e.g., episodic versus long-term). This study found important differences across cancer patients with varying histories of anxiety/depression, with people who had a history of long-term anxiety/depression that was not associated with cancer generally coping better, experiencing less fear of cancer recurrence, and requiring less support from hospitals and support services. These results highlight a need for both researchers and health professionals to give more consideration to the origin and history of a cancer patient's anxiety/depression in order to facilitate better coping and improve and increase appropriate support provision across cancer diagnosis, treatment, and survivorship.

Overall, across the research in this thesis, subjective illness representations such as personal control, consequences, timeline, and illness coherence, have been found to be important predictors of coping behaviours, self-management strategies, and illness outcomes in people with cancer, people with depression, and people with co-morbid cancer and anxiety/depression, supporting the importance of the CSM as a theoretical basis from which to explore such representations. Further, multimorbid representations such as combined or competing causal representations, prioritisation of a perceived most challenging illness, beliefs about fear of cancer recurrence, and synergies/antagonisms in the management of illnesses, were found to be associated with self-management strategies and illness outcomes

in people with co-morbid cancer and anxiety/depression, with the support needs of these people found to vary based on their history with anxiety/depression.

The discovery of these multimorbid illness representations suggests that the CSM may need to be adapted to be more appropriate for people with multiple illnesses. These findings also highlight the need for future research to trial interventions aimed at changing incorrect or maladaptive representations for people with cancer, people with depression, and people with both cancer and anxiety/depression. At the same time, the findings of this thesis highlighted the role of support providers in improving outcomes for people with cancer and anxiety/depression, suggesting a need for increased understanding of illness representations and illness history by providers, improved communication between patients and health professionals, and increased support provision and access to psycho-oncological services for patients.

## **Acknowledgements**

The completion of this thesis would not have been possible without contributions from a number of amazing people. Firstly, I must thank my supervisory team for their continued guidance and assistance throughout the three year journey. Ben, you have been a better supervisor than I could have ever hoped for; you have always made time for me, given me thoughtful and timely feedback, and provided me with an overall excellent research training experience. What you have taught me will hold me in good stead for a career in psychology and I hope we can continue to collaborate in future. Jenn, thank you for teaching me about qualitative research, for your valuable feedback on every project, and for your optimistic approach to publication. Thank you also to Kristy and Natalie for always providing thoughtful feedback and suggestions, as well as a word of encouragement when needed. All four of you are excellent researchers and fantastic people, and I am extremely grateful to have had your support throughout my PhD candidature.

My appreciation also goes to the University of Tasmania, the Australian Government, and the sponsors of the Jim Bacon Memorial Scholarship for their financial support during my candidature. Additionally, I wish to thank Penny Egan (CEO of Cancer Council Tasmania), Cynthia Taafe, and Karen Rogers for allowing me to recruit participants through Cancer Council Tasmania, to use the support room at Cancer Council Tasmania, and for their continued support of me and of my research. I would also like to thank each participant involved in this project, your valuable and selfless contributions have the power to improve the lives of others with cancer.

I would also like to acknowledge my beautiful family and friends, without whom I would not be the person I am, nor would I have completed this thesis. In particular, I must thank my mum for attempting to teach me when to slow down, and my dad for encouraging me to continue my studies. I love and thank you both for everything you have done and

continue to do for me. Mark, you are a wealth of knowledge and a fantastic brother, thank you for always being there when I need. To my wonderful friends, Jane for helping to code my interviews, Lil and Kim for sharing in the PhD joy/pain, Maz for always being there, and the BHPs for being the best netballers and friends a person could ask for, thank you. Lastly, Marty (and the pugs), thank you for your unwavering belief in me, your part in building our beautiful home, and for working so hard over the last few years. Your love and support has been essential to the success of my PhD, and I cannot wait for our next adventure together.

## Table of Contents

<b>Declaration of Originality .....</b>	<b>i</b>
<b>Authority of Access Statement.....</b>	<b>ii</b>
<b>Statement Regarding Published Work Contained in Thesis .....</b>	<b>iii</b>
<b>Statement of Co-Authorship .....</b>	<b>iv</b>
<b>Statement of Ethical Conduct .....</b>	<b>vii</b>
<b>Abstract.....</b>	<b>viii</b>
<b>Acknowledgements .....</b>	<b>xii</b>
<b>Table of Contents .....</b>	<b>xiv</b>
<b>List of Tables .....</b>	<b>xix</b>
<b>List of Figures.....</b>	<b>xx</b>
<b>Chapter 1: Introduction .....</b>	<b>1</b>
<b>Cancer Prevalence and Associated Outcomes .....</b>	<b>2</b>
<b>Co-morbid Cancer and Anxiety/Depression .....</b>	<b>3</b>
<b>The Common Sense Model of Health and Illness .....</b>	<b>6</b>
<i>Illness Representations .....</i>	<i>7</i>
<i>The CSM in Practice .....</i>	<i>9</i>
<i>The CSM and Chronic Illness.....</i>	<i>10</i>
<i>The CSM and Cancer .....</i>	<i>11</i>
<i>The CSM and Mental Illness .....</i>	<i>13</i>
<b>Co-morbid Illness Representations.....</b>	<b>16</b>
<b>Comparing Support Needs across People with Cancer and Anxiety/Depression .....</b>	<b>19</b>
<b>The Present Thesis .....</b>	<b>20</b>
<i>Study 1 (Chapter 2) Aim .....</i>	<i>21</i>
<i>Study 2 (Chapter 3) Aim .....</i>	<i>22</i>
<i>Study 3 (Chapter 4) Aim .....</i>	<i>22</i>
<i>Study 4 (Chapter 5) Aim .....</i>	<i>23</i>
<b>Chapter 2: Study 1 .....</b>	<b>25</b>
<b>Illness representations, coping, and illness outcomes in people with cancer: A systematic review and meta-analysis .....</b>	<b>25</b>
<b>Abstract .....</b>	<b>26</b>
<b>Background.....</b>	<b>27</b>
<i>Illness Representations and the Common Sense Model .....</i>	<i>27</i>

<i>Illness Representations in Cancer: The Present Review</i> .....	29
<i>Aims and Hypotheses</i> .....	30
<b>Methods</b> .....	<b>30</b>
<i>Literature Search, Inclusion Criteria, and Study Selection</i> .....	30
<i>Classification of Coping Behaviours and Illness Outcomes</i> .....	32
<i>Data Extraction and Meta-Analytic Strategy</i> .....	33
<b>Results</b> .....	<b>34</b>
<i>Study Characteristics</i> .....	34
<i>Risk of Bias Assessment</i> .....	35
<i>Relationship of Illness Representations to Coping Behaviours: Quantitative Analysis</i> ...	36
<i>Relationship of Illness Representations to Illness Outcomes: Quantitative Analysis</i> .....	38
<i>Moderator Analyses</i> .....	39
<i>Relationship of Illness Representations to Coping Behaviours: Narrative Review</i> .....	43
<i>Relationship of Illness Representations to Illness Outcomes: Narrative Review</i> .....	44
<b>Discussion</b> .....	<b>45</b>
<i>Implications and Future Research Directions</i> .....	47
<i>Strengths and Limitations</i> .....	48
<b>Conclusions</b> .....	<b>50</b>
<b>Chapter 3: Study 2</b> .....	<b>51</b>
<b>Illness representations, coping, and illness outcomes in depression: A systematic review and meta-analysis</b> .....	<b>51</b>
<b>Abstract</b> .....	<b>52</b>
<b>Introduction</b> .....	<b>53</b>
<b>Method</b> .....	<b>57</b>
<i>Literature Search, Inclusion Criteria, and Study Selection</i> .....	57
<i>Coding of Coping Behaviours and Illness Outcomes</i> .....	59
<i>Data Extraction and Meta-Analytic Strategy</i> .....	64
<b>Results</b> .....	<b>65</b>
<i>Study Characteristics</i> .....	65
<i>Risk of Bias Assessment</i> .....	65
<i>Relationship of Illness Representations to Coping and Psychological Distress: Quantitative Analysis</i> .....	66
<i>Relationship of Illness Representations to Coping and Psychological Distress: Narrative Review</i> .....	67



<b>Discussion .....</b>	<b>71</b>
<i>Illness Representations and Coping Behaviours .....</i>	<i>71</i>
<i>Illness Representations and Illness Outcomes .....</i>	<i>72</i>
<i>Implications .....</i>	<i>73</i>
<i>Limitations .....</i>	<i>73</i>
<i>Conclusion .....</i>	<i>75</i>
<b>Chapter 4: Study 3 .....</b>	<b>76</b>
<b>‘It was all intertwined’: Illness representations and self-management in people with cancer and anxiety/depression .....</b>	<b>76</b>
<b>Abstract .....</b>	<b>77</b>
<b>Introduction .....</b>	<b>78</b>
<b>Method.....</b>	<b>81</b>
<i>Participants .....</i>	<i>81</i>
<i>Materials.....</i>	<i>82</i>
<i>Procedure .....</i>	<i>82</i>
<i>Analysis.....</i>	<i>83</i>
<b>Results .....</b>	<b>84</b>
<i>Demographics and Illness Characteristics .....</i>	<i>84</i>
<i>Thematic Analysis.....</i>	<i>84</i>
<b>Discussion .....</b>	<b>96</b>
<i>Limitations .....</i>	<i>99</i>
<i>Implications .....</i>	<i>101</i>
<i>Conclusion .....</i>	<i>102</i>
<b>Chapter 5: Study 4 .....</b>	<b>104</b>
<b>A qualitative comparison of the support needs of people with cancer based on their history of anxiety/depression .....</b>	<b>104</b>
<b>Abstract .....</b>	<b>105</b>
<b>Introduction .....</b>	<b>106</b>
<b>Method.....</b>	<b>108</b>
<i>Participants .....</i>	<i>108</i>
<i>Materials.....</i>	<i>108</i>
<i>Procedure .....</i>	<i>108</i>
<i>Analysis.....</i>	<i>109</i>
<b>Results .....</b>	<b>110</b>

<i>Demographics and Illness Characteristics</i> .....	110
<i>DASS-21</i> .....	112
<i>Thematic Analysis</i> .....	113
<b>Discussion</b> .....	<b>117</b>
<i>Implications</i> .....	119
<i>Limitations</i> .....	120
<i>Conclusions</i> .....	121
<b>Chapter 6: Discussion</b> .....	<b>122</b>
<b>Summary of the Main Findings</b> .....	<b>125</b>
<i>Illness Representations, Coping Behaviours, and Illness Outcomes in People with Cancer, Anxiety, and/or Depression</i> .....	125
<i>Support Needs for People with Cancer and Anxiety/Depression</i> .....	130
<b>Theoretical Implications and Future Research Directions</b> .....	<b>132</b>
<i>Role of the CSM in Cancer and Anxiety/Depression</i> .....	132
<i>Expanding the CSM</i> .....	134
<b>Practical Implications and Future Research Directions</b> .....	<b>136</b>
<i>Future CSM Interventions</i> .....	136
<i>Health Professionals' Understanding of Illness Representations</i> .....	142
<i>Challenge of Co-Morbid Cancer and Anxiety/Depression for Support Provision</i> .....	143
<i>Provision of Appropriate Support and Information</i> .....	146
<b>Limitations</b> .....	<b>146</b>
<i>Sample</i> .....	147
<i>Research Design</i> .....	149
<b>Conclusions</b> .....	<b>151</b>
<b>References</b> .....	<b>152</b>
<b>Appendices</b> .....	<b>183</b>
<b>Appendix 2.1</b> Published version of Study 1 (Chapter 2).....	<b>183</b>
<b>Appendix 2.2</b> PRISMA 2009 Statement (Study 1) .....	<b>197</b>
<b>Appendix 2.3</b> Database search strategies (original search) (Study 1) .....	<b>199</b>
<b>Appendix 2.4</b> Coding manual (Study 1).....	<b>201</b>
<b>Appendix 2.5</b> Coding sheet (Study 1) .....	<b>224</b>
<b>Appendix 2.6</b> Study selection process (Study 1).....	<b>228</b>
<b>Appendix 2.7</b> Quantitative data extraction and study characteristics table (Study 1).....	<b>230</b>
<b>Appendix 2.8</b> Qualitative data extraction and study characteristics table (Study 1).....	<b>235</b>

<b>Appendix 2.9</b> Meta-analytic strategy – additional information (Study 1).....	<b>237</b>
<b>Appendix 2.10</b> Risk of bias assessment (Study 1) .....	<b>239</b>
<b>Appendix 2.11</b> Meta-analysis forest plots between illness representations and coping behaviours and illness representations and illness outcomes (Study 1).....	<b>247</b>
<b>Appendix 2.12</b> Meta-analysis funnel plots between illness representations and coping behaviours and illness representations and illness outcomes (Study 1).....	<b>258</b>
<b>Appendix 3.1</b> PRISMA 2009 Statement (Study 2) .....	<b>267</b>
<b>Appendix 3.2</b> Database search strategies (Study 2) .....	<b>269</b>
<b>Appendix 3.3</b> Coding manual (Study 2).....	<b>270</b>
<b>Appendix 3.4</b> Coding sheet (Study 2) .....	<b>290</b>
<b>Appendix 3.5</b> Risk of bias assessment table (Study 2).....	<b>294</b>
<b>Appendix 3.6</b> Risk of bias assessment and figure (Study 2) .....	<b>297</b>
<b>Appendix 3.7</b> Meta-analysis forest plots between illness representations and coping and illness representations and psychological distress (Study 2) .....	<b>301</b>
<b>Appendix 3.8</b> Meta-analysis funnel plots between illness representations and coping and illness representations and psychological distress (Study 2) .....	<b>304</b>
<b>Appendix 4.1</b> Interview guide (Study 3 and Study 4).....	<b>306</b>
<b>Appendix 4.2</b> COREQ checklist (Study 3) .....	<b>313</b>
<b>Appendix 4.3</b> Demographics and DASS-21 Stress subscale scores (Study 3).....	<b>315</b>
<b>Appendix 5.1</b> Additional methodological information (Study 4) .....	<b>316</b>
<b>Appendix 5.2</b> COREQ checklist (Study 4) .....	<b>318</b>

## List of Tables

<b>Table 2.1</b> Meta-analyses of the relationships between illness representations and coping behaviours .....	<b>37</b>
<b>Table 2.2</b> Meta-analyses of the relationships between illness representations and anxiety, and illness representations and depression .....	<b>40</b>
<b>Table 2.3</b> Meta-analyses of the relationships between illness representations and psychological distress, and consequences and psychological well-being .....	<b>41</b>
<b>Table 2.4</b> Meta-analyses of the relationships between illness representations and role functioning, illness representations and physical functioning, and illness representations and quality of life.....	<b>42</b>
<b>Table 3.1</b> Data extraction and study characteristics .....	<b>61</b>
<b>Table 3.2</b> Meta-analyses of the relationships between illness representations and coping, and illness representations and psychological distress .....	<b>68</b>
<b>Table 4.1</b> Illness characteristics and DASS-21 anxiety and depression subscale scores .....	<b>85</b>
<b>Table 5.1</b> Participant groupings based on history of cancer and anxiety/depression.....	<b>110</b>
<b>Table 5.2</b> Demographics and illness characteristics.....	<b>111</b>
<b>Table 6.1</b> Summary of the findings in the present thesis .....	<b>124</b>

## List of Figures

<b>Figure 1.1</b> The common sense model of self-regulation of health and illness (Leventhal et al., 1980), adapted from Diefenbach and Leventhal (1996) .....	<b>7</b>
<b>Figure 2.1</b> The common sense model of self-regulation of health and illness (Leventhal et al., 1980), adapted from Diefenbach and Leventhal (1996) .....	<b>28</b>
<b>Figure 2.2</b> Flow-chart of the study selection process.....	<b>32</b>
<b>Figure 3.1</b> The common sense model of self-regulation of health and illness (Leventhal et al., 1980), adapted from Diefenbach and Leventhal (1996) .....	<b>55</b>
<b>Figure 3.2</b> Flow chart of the study selection process .....	<b>60</b>
<b>Figure 4.1</b> Thematic map of representations of cancer and anxiety/depression and their relationships with coping and self-management strategies.....	<b>87</b>
<b>Figure 5.1</b> Thematic map comparing support needs of people with cancer and anxiety/depression.....	<b>114</b>

## **Chapter 1**

### **Introduction**

## **Cancer Prevalence and Associated Outcomes**

Worldwide there were approximately 14 million new cancer cases in 2012, with almost 32.5 million cancer patients/survivors within the first five years of their diagnosis (International Agency for Research on Cancer & World Health Organisation, 2014). In Australia, cancer is one of the most commonly experienced diseases, with the risk of receiving a cancer diagnosis before the age of 85 years one in two for males and one in three for females (Cancer Australia, 2016). With regard to cancer prevalence, in Australia in 2012 there were 122,093 new cancer cases diagnosed at an age-standardised incidence rate of 485 cases per 100,000 people (Australian Institute of Health and Welfare [AIHW], 2016), with this number expected to grow to an estimated 130,466 people in 2016 (Cancer Australia, 2016). In terms of mortality, although 44,108 people died from cancer in 2013, the age-standardised mortality rate for all cancers has fallen by approximately 20% from 1982 to now (AIHW, 2014). The reasons for this drop in mortality are mainly attributed to increases in early detection rates and improved treatment methods (Alfano & Rowland, 2006; Stewart & Wild, 2014). Because of these advances and the associated drop in mortality rates, people with cancer are now living longer, with 1.7% of the Australian population, or 370,474 people, living with cancer at the end of 2009 (after being diagnosed in the previous five years). Furthermore, 67% of people diagnosed with cancer are now surviving for at least five years' post-diagnosis (between 2007-2011; AIHW, 2014), with better psychosocial support needed to improve the outcomes for these cancer patients and survivors.

The improved survival rate for people diagnosed with cancer means that a considerable proportion of the Australian population live with the continued effects of cancer. These effects include both physical post-treatment side effects and mental health problems such as fatigue, poor role and physical functioning, psychological distress, cognitive impairment, anxiety, depression, fear of cancer recurrence, and a poorer quality of life

(Ahles, Root, & Ryan, 2012; Edwards & Clarke, 2004; Harrington, Hanse, Moskowitz, Todd, & Feuerstein, 2010; Simard et al., 2013; Singer, Das-Munshi, & Brähler, 2010; Stein, Syrjala, & Andrykowski, 2008). Further, these poor mental and physical health outcomes are often long-term (Stein et al., 2008). One systematic review for example found that survivors experienced poor outcomes for up to ten years post diagnosis (Harrington et al., 2010). To both cope with and self-manage these outcomes is an extraordinary challenge for cancer patients and survivors. However, the use of particular adaptive coping strategies, such as cognitive reappraisal and problem-focused coping, can improve adjustment to cancer (O'Brien & Moorey, 2010). Further, productive and proactive self-management strategies can be facilitated by appropriate self-management interventions and partnerships between patients and health care providers. Such self-management strategies have been found to decrease symptom distress and uncertainty, and improve communication and quality of life (McCorkle et al., 2011). However, the effectiveness of such interventions could be improved by better matching them with people's needs, their ideas about their illnesses, and their subjective understanding of their illnesses, as cancer-related perceptions have been found to influence coping responses and illness outcomes (e.g., treatment decision making: Kendel et al., 2016). This thesis therefore provides an examination of the dimensions and parameters of these subjective ideas, perceptions, understandings, and needs in people with cancer and anxiety/depression.

### **Co-morbid Cancer and Anxiety/Depression**

Nearly all people with cancer experience some psychological distress after being diagnosed and throughout their treatment. However, for many this distress is short-term, meaning that when they recover from their cancer they are likely to re-gain psychological health and equilibrium, with few significant long-term effects experienced (Stein et al., 2008). For others, however, the cancer experience can lead to more severe psychological



impairment, which is evident in the high number of diagnoses of mental illnesses in cancer patients. The most prominent of these co-morbid mental illnesses are anxiety and depression. However, reported prevalence rates vary due to differing conceptualisations of illness, measurement techniques, and populations of interest (Massie, 2004; Pasquini & Biondi, 2007). An examination of the prevalence rates of depression amongst people with cancer in 60 studies found prevalence rates ranging up to 52%, stating that the association between cancer and high levels of depression is beyond doubt (Massie, Lloyd-Williams, Irving, & Miller, 2011). Although rates of anxiety amongst people with cancer also vary, it has been suggested that anxiety co-occurs with cancer at an equivalent or greater rate than depression (Mystakidou et al., 2005; Roy-Byrne et al., 2008).

Both anxiety and depression in cancer patients can be specifically associated with the cancer itself, or relate to pre-existing anxiety or depression (Fulcher, Kim, Smith, & Sherner, 2014; Jacobsen, Donovan, Swaine, & Watson, 2006; Mehta & Roth, 2015; Stark & House, 2000). More specifically, sources of anxiety and depression amongst cancer patients include pre-existing diagnoses (mental illness predating a cancer diagnosis) that may be re-activated or exacerbated by the cancer experience, acute or chronic reactions to the diagnosis of cancer, the disruption of life plans, adverse responses to cancer symptoms or treatment side-effects, the effect of treatment on the central nervous system, reduced quality of life, and fears associated with cancer progression or recurrence (Jacobsen et al., 2006). Experiences of depression and anxiety are not limited to the active treatment stage of the cancer process but often persist for months or years post treatment. A key source of this long-term anxiety and/or depression is greater stress and burden associated with the cancer experience, coupled with a lack of available resources (Stein et al., 2008).

As cancer is often associated with coping difficulties and poor health outcomes, it can be assumed that an additional diagnosis of anxiety and/or depression would only increase

such coping difficulties and compound poor outcomes. Research supports this assumption, with co-morbid cancer and anxiety/depression found to be associated with poorer social, emotional, and role functioning, adherence to treatment, and several domains of quality of life (including overall) (L. F. Brown, Kroenke, Theobald, Wu, & Tu, 2010; Mystakidou et al., 2005; Pasquini & Biondi, 2007). With regard to employment, co-morbid cancer and anxiety/depression have been associated with an increase in disability days (days in bed or with a >50% reduction in work/usual activities) and with an inability to work (Kroenke et al., 2010). Perhaps the most concerning findings for this population are however that co-morbid depression can predict elevated mortality (Pinquart & Duberstein, 2010; Satin, Linden, & Phillips, 2009), increase the risk of suicide (Misono, Weiss, Fann, Redman, & Yueh, 2008; Robinson, Renshaw, Okello, Moller, & Davies, 2009; Robson, Scrutton, Wilkinson, & MacLeod, 2010), and increase the desire for hastened death by up to four times in terminally ill cancer patients (Breitbart, Rosenfeld, Pessin, & et al., 2000).

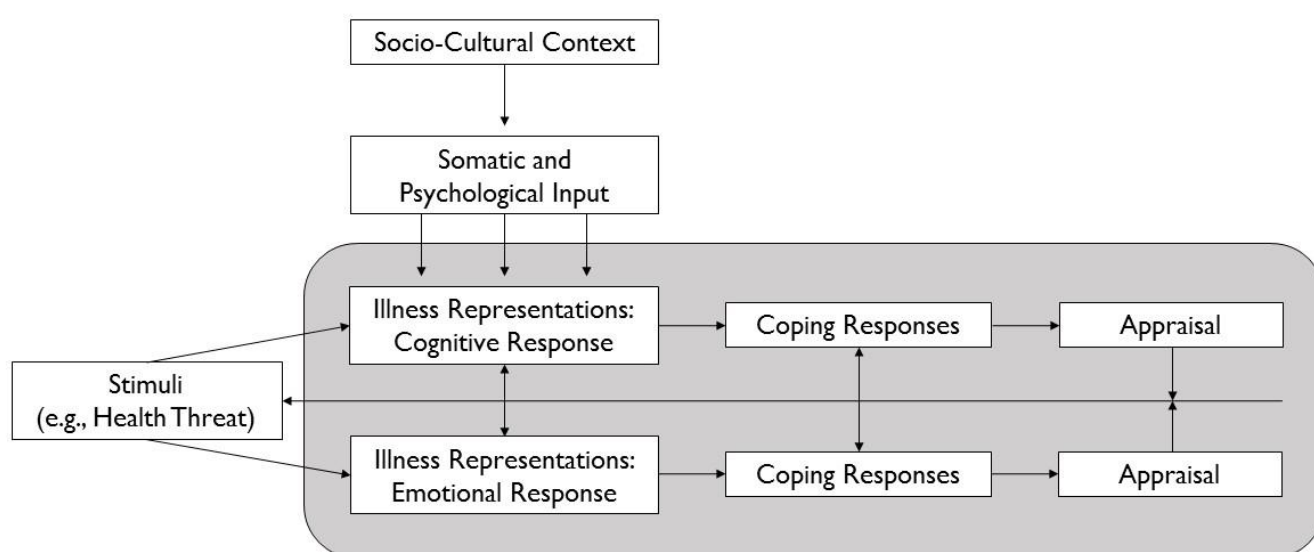
In order to increase adaptive coping responses and improve the poor health outcomes associated with the co-morbid experience of cancer and anxiety/depression, we need to learn more about the factors that are influencing these outcomes, with people's cognitive representations of illness (understanding of their illnesses) one such influencing factor. A better understanding of these cognitive representations can provide a greater insight into how people think about and experience their illnesses. In addition to this, an examination of how these cognitive representations may influence the coping and self-management of, as well as the illness outcomes associated with, cancer and anxiety/depression is needed. This new knowledge could in turn lead to improvements in current interventions, or the development of new effective support measures and future interventions that improve the health and well-being of people with these illnesses. This appears to be an area in need of innovation, as current evidence from systematic and meta-analytic reviews have mixed outcomes and

disparate conclusions regarding the effectiveness of interventions for cancer patients with psychological distress, anxiety, and depression (Galway et al., 2012; Jacobsen & Jim, 2008; Lepore & Coyne, 2006). This thesis will therefore attempt to examine the relationships between cognitive representations and illness outcomes in people with cancer and anxiety/depression with a view to improving future interventions.

### **The Common Sense Model of Health and Illness**

The most widely used model of the psychological processes underlying coping behaviours and health outcomes in people with chronic illness is the Common Sense Model of Self-Regulation of Health and Illness (CSM; Leventhal, Meyer, & Nerenz, 1980). The CSM aims to explain how people understand and respond to a health threat or illness. The model conceptualises an individual as an active problem solver who is required to manage two phenomena in parallel, their perceptions or representations of a health threat (e.g., symptoms, being told that something is wrong by a doctor, or encountering an advertisement related to an illness) or illness (*what is this health threat or illness, and what can I do about it*), and their associated emotional responses to that health threat or illness (*how do I feel about the health threat or illness and how can I feel better about it*) (Diefenbach & Leventhal, 1996). The model is hierarchically organised, with three main constructs: illness representations, coping responses, and appraisal. Illness representations, people's interpretation of or beliefs about a health threat or illness, and emotional responses, are formed based on existing schemata including current and past illness experience, information from the external social environment, and general knowledge (Leventhal et al., 1980). These cognitive representations, as well as their associated emotional responses, work in parallel to guide coping responses and self-management strategies, which are later appraised in terms of their success or failure in controlling the health threat and its consequences (Hale, Treharne, & Kitas, 2007). Outcome appraisals then lead to the refinement of one's illness

representations, as well as the selection of new coping and management strategies (Diefenbach & Leventhal, 1996). The CSM includes illness representations, coping responses, and appraisal, as part of a multi-directional and self-regulative feedback loop (see Figure 1.1), meaning that these processes are subject to change and evolution over time (Leventhal, Leventhal, & Contrada, 1998).



*Figure 1.1.* The common sense model of self-regulation of health and illness (Leventhal et al., 1980), adapted from Diefenbach and Leventhal (1996).

### *Illness Representations*

The key construct within the CSM are subjective illness representations (sometimes referred to as illness perceptions), defined as individual's lay beliefs about illness. This means that rather than being accurate and correct, these representations encompass what people understand about the illness and what they believe to be accurate and correct. These representations are how people make sense of their illness, and according to the theory, they

explain how individuals attempt to cope with their illness (Hale et al., 2007; Leventhal et al., 1998; Leventhal et al., 1980). The model proposes several distinct illness representation dimensions: identity, cause, timeline (acute/chronic), timeline (cyclical), consequences, curability/controllability, personal control, treatment control, illness coherence, and emotional representations (Diefenbach & Leventhal, 1996; Leventhal et al., 1998; Leventhal et al., 1980; Moss-Morris et al., 2002). *Identity* refers to the label or name of the health threat or illness (e.g., cancer) and its symptoms (e.g., weight loss). *Cause* refers to the perceived cause of the health threat or illness (e.g., poor diet). *Timeline* refers to beliefs about the length of illness development, duration, and recovery (e.g., acute or chronic). *Consequences* (both imagined and real) refers to beliefs about the anticipated repercussions associated with the health threat or illness (e.g., financial hardship). *Curability* or *Controllability* refers to the perceived belief about the extent to which the health threat or illness can be prevented, controlled, prevented from progressing, or cured, by themselves or by others (e.g., controllable and curable with medication) (Diefenbach & Leventhal, 1996; Leventhal et al., 1998).

Later revisions of the illness representation dimensions proposed that control beliefs could be separated into two distinct dimensions: *personal control* – the amount of control an individual perceives that they personally have over the health threat or illness, and *treatment control* - the amount of control an individual perceives their treatment has over the health threat or illness. These revisions also included a distinct dimension for *cyclical timeline* perceptions, as well as an *illness coherence* dimension referring to the extent to which an individual demonstrates coherent understanding of the health threat or illness (e.g., confused by symptoms), and an *emotional representations* dimension that refers to an individual's emotional responses to the health threat or illness (e.g., anxious) (Moss-Morris et al., 2002). The Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996),

the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002), and the Brief Illness Perception Questionnaire (B-IPQ; Broadbent, Petrie, Main, & Weinman, 2006), are the most widely used instruments to assess these illness representations. The IPQ-R has demonstrated acceptable test-retest reliability at three weeks and six months, sound discriminant and predictive validity, and good internal reliability, with Cronbach alpha's ranging between .79 and .89 across subscales (Moss-Morris et al., 2002).

### *The CSM in Practice*

How individuals' illness beliefs may influence the way in which they cope with and manage a health threat or illness can be explained by the CSM. For example, when experiencing a health threat such as a headache, a person will automatically attempt to find the location of the pain and try to establish its cause (accessing illness representations), considering factors like the sharpness of the pain, dehydration, or whether a similar pain has been experienced previously. How this person will then cope with and treat the headache depends on the answers to these questions. Potential outcomes include visiting a doctor or health professional (for example, if they interpret the pain to be a symptom of an underlying illness), taking pain relieving medication (for example, if they know they are prone to a headache when they have slept badly), asking for advice from a friend or family member (for example, if they have a friend who has medical training), increasing hydration (for example, if they have read that dehydration can lead to headaches), or waiting to see whether the pain subsides on its own (for example, if this strategy was effective previously). This evaluation and decision-making process is influenced by three key sources of information, bodily experiences (e.g., the location of the headache), information based on previous experiences with illness (e.g., a previous diagnosis of cancer), and information gathered from the external social environment (e.g., from family and friends, health professionals, and the media) (Leventhal et al., 1980). Cultural and social factors (e.g., "My family told me to stop getting

upset over nothing”), as well as emotional responses to the health threat (headache; e.g., “I’m afraid my cancer may have returned”), also play a key role in this process (Diefenbach & Leventhal, 1996).

Once a coping response has been chosen and enacted, the person will evaluate or appraise the effectiveness of that response. For example, if the person had attempted to alleviate their headache by increasing hydration levels, they might ask themselves whether this was successful and whether they feel any better. If the headache is not relieved with additional hydration, the individual will then revise their illness representations and initial self-diagnosis, as well as seek an alternative explanation for the headache (for example, by visiting a health professional). Emotional responses are also generated in parallel with this cognitive process, for example, for a person with a previous cancer diagnosis, a headache might provoke extreme anxiety, and could lead the person to engage in behaviours that may reduce this fear. The CSM thus suggests that coping responses (and later appraisal) are performed with respect to the emotional responses elicited by a health threat, as well as by the cognitive activity that generates the representations of the health threat (Diefenbach & Leventhal, 1996). It is thought that this process may be more complex for people who experience multiple health threats or illnesses, where multimorbid representations may impact coping behaviours and health outcomes. For example, co-morbid anxiety/depression are often experienced with chronic illnesses and may result in maladaptive cognitions (e.g., catastrophising or hopelessness), which in turn may negatively influence coping attempts and illness self-management.

### *The CSM and Chronic Illness*

The CSM and the illness representation dimensions have been instrumental in helping to understand how people respond to and experience chronic illness. A seminal systematic review by Hagger and Orbell (2003) summarised how the illness representation dimensions

measured by the IPQ are related to coping behaviours and illness outcomes. In particular, they found that greater perceived controllability over an illness was associated with more adaptive coping strategies (e.g., cognitive reappraisal, problem-focused coping), while perceiving an illness as highly symptomatic with a chronic timeline and serious consequences was associated with more maladaptive coping strategies (e.g., avoidance/denial, expressing emotion). With regard to illness outcomes, perceptions of the illness as curable and controllable were associated with more positive illness outcomes (e.g., psychological well-being, vitality), while perceptions of increased symptomology (higher identity), a chronic timeline, and more severe consequences were associated with negative illness outcomes (e.g., psychological distress). A more recent meta-analytic review by Dempster, McCorry, and Howell (2015) found further support for the relationship between illness representations and psychological distress over a range of physical health conditions, with higher identity (more perceived symptoms), more serious consequences, a more cyclical timeline, higher emotional representations (a stronger emotional response), less controllability, and less illness coherence, associated with higher levels of depression and anxiety. The associations identified across both of these reviews provide strong support for the CSMs illness representation dimensions, and highlight the importance of understanding individuals' subjective illness representations.

### *The CSM and Cancer*

Despite the important insights provided by Hagger and Orbell (2003) and Dempster et al. (2015), neither review explicitly examined the relationships between illness representations, coping, and outcomes, in people with cancer or in people with anxiety/depression (or allowed for separate results by illnesses). Therefore, in order to appropriately examine and understand how illness representations relate to coping behaviours and illness outcomes in people with these illnesses, this thesis provides the first systematic



reviews with meta-analyses of these relationships (Study 1 and Study 2).

Interest in the relationships between illness representations and coping behaviours and illness representations and illness outcomes in people with cancer specifically has increased over time, with the number of publications examining the CSM in the cancer domain steadily increasing (particularly since the creation of the IPQ; Weinman et al., 1996). The illness representations held by people with cancer may be particularly relevant to understanding how people with cancer cope and function, as research has shown that cancer patients have strong and easily accessible representations based on illness experience that differ from the representations of people without a cancer diagnosis (Anagnostopoulos & Spanea, 2005; Buick & Petrie, 2002). Due to the differing nature of these representations, explorations of the relationships between representations, coping, and outcomes in people with cancer specifically were required.

Illness representations appear to be particularly relevant for coping behaviours and illness outcomes in people with cancer. For example, Gould, Brown, and Bramwell (2010) found higher perceived personal control to be associated with more adaptive coping strategies (e.g., problem-focused coping and acceptance/growth), while perceptions of a more cyclical timeline and less illness coherence were associated with maladaptive coping strategies (e.g., denial/disengagement), in people with gynaecological cancer. With respect to illness outcomes, Dempster et al. (2012) found perceptions of a more chronic or cyclic timeline, more severe consequences, less personal and treatment control, and less illness coherence, to be associated with higher levels of depression and anxiety in people with oesophageal cancer.

At times the size and direction of the associations between illness representations, coping, and outcomes, in people with cancer have been found to vary across studies. For example, Keeling, Bambrough, and Simpson (2013) found a moderate negative relationship between illness coherence and anxiety in people with low-grade brain tumours, suggesting

that less understanding of their cancer was associated with higher levels of anxiety. In contrast, Freeman-Gibb (2012) found a negligible positive relationship between illness coherence and anxiety in people with breast cancer, suggesting that a better understanding of their cancer was associated with more anxiety, though the negligible size of the effect suggests that this association is weak and may not be particularly meaningful. Both the large number of studies examining illness perceptions in people with cancer, as well as the inconsistencies in findings across some studies, warranted the completion of a systematic review and meta-analysis to determine whether illness representations are related to coping behaviours and illness outcomes across studies of people with cancer, as well as to clarify the strength and direction of these relationships (Study 1).

### *The CSM and Mental Illness*

No study has quantitatively synthesised the literature examining the relationships between illness representations, coping behaviours, and illness outcomes, in people with anxiety/depression. Therefore, in order to address this gap in the literature, as well as to find out whether it would be appropriate to use the CSM as a basis for examining the representations of people with co-morbid cancer and anxiety/depression (Study 3), this thesis included a systematic review and meta-analysis to specifically examine the relationships between illness representations, coping, and outcomes in people with anxiety and/or depression (Study 2).

The CSM was originally designed to explain how cognitive structures and representations can explain coping responses in people with physical illnesses. However, the model has also been found to be useful for examining and understanding how people's representations can influence coping behaviours and illness outcomes in mental illnesses. For example, Elwy, Yeh, Worcester, and Eisen (2011) found those who sought treatment for depression had perceptions of a better understanding of depression (higher illness coherence)

and perceived treatment would control their depression (higher treatment control), while those who did not seek treatment for depression perceived that treatment would not control their depression (lower treatment control) and that the depression would be short-term (acute timeline). With regard to illness outcomes, Lu et al. (2014) found that perceived chronic timeline, more severe consequences, stronger emotional representations, and less perceived personal control were associated with depression severity, anxiety, stress, and psychological distress, in people with depression. Further, two recent reviews have offered support for the illness representation dimensions of the CSM in people with mental illness and depression respectively (Alderson, Foy, Glidewell, McLintock, & House, 2012; Baines & Wittkowski, 2013).

Alderson et al. (2012) used a narrative synthesis to examine beliefs about depression in people with current depressive symptoms. Beliefs were coded into the main categories of illness representations, though five additional thematic categories were found for beliefs that did not clearly fit within the CSM framework (understandability, the depression cycle, existential and self, suicidal thinking, and stigma, blame, and responsibility). They noted that illness representations in depression may be more complex than those in physical illnesses, highlighting the marked variations between participants across depression identity and timeline beliefs, with many different labels used to describe depression, and acute, chronic, and cyclic timelines all mentioned. Further, most study participants perceived complex multi-factor causes for their depression, held strong beliefs about treatment control, and felt that depression had mostly negative consequences that affected all current and future aspects of life (e.g., physical health, social and home life), with some participants experiencing a lack of any control over depression. Finally, there was difficulty in distinguishing between an emotional representation for depression and the emotional symptoms of depression, though depression was found to be associated with fear, anxiety, sadness, despair, and guilt. When

examining these findings, a consideration of the three key elements of Beck's cognitive triad (A. T. Beck, 1967), negative views about the self, world, and future, may help to explain how depression influences subjective representations through negative automatic thoughts (A. T. Beck, Rush, Shaw, & Emery, 1979). For example, a negative view of the future may lead to perceptions of a more chronic timeline of depression, while negative self and world views may lead to perceptions of less control over depression. Although this study provided insight into how the experience of depressive symptoms may be related to the illness representation dimensions, no formal review of how representations could impact coping and outcomes was included.

More recently, a systematic review examining the relationships between illness representations and coping behaviours and illness representations and illness outcomes in people with mental illness was conducted by Baines and Wittkowski (2013) across 13 studies. This review included a qualitative synthesis and summary of four studies that specifically examined the representations of people with depression, though no such summary was included for studies of people with anxiety. This summary revealed that perceptions of more negative consequences and a higher identity were associated with the use of maladaptive coping strategies (e.g., self-blame); perceptions of a more chronic timeline was associated with increased medication adherence and treatment seeking; and perceptions of a higher identity, more chronic timeline, more severe consequences, and less personal control were associated with increased depression severity.

The CSM has increased understanding of how people self-regulate, manage, and cope with physical illnesses (Dempster et al., 2015; Hagger & Orbell, 2003). Further, research examining illness representations in people with mental illness has demonstrated the CSMs applicability for also understanding how people self-regulate mental illnesses (Alderson et al., 2012; Baines & Wittkowski, 2013). However, in order to further understand how the

CSM can inform coping and outcomes in people with anxiety/depression specifically, a systematic review and meta-analysis of the relationships between illness representations and coping behaviours, as well as illness representations and illness outcomes, in this population was required (Study 2), something not yet examined in previous review studies.

### **Co-morbid Illness Representations**

As previously highlighted, many quantitative and qualitative studies across multiple single chronic illnesses (e.g., diabetes, cancer, asthma, depression) have used the CSM as a basis for improving our understanding of illness behaviour. In particular, this research highlights the relationships between the CSMs illness representation dimensions and coping behaviours as well as illness outcomes. However, given the high prevalence of co-existing multiple illnesses (multimorbidity, co-morbidity), examining illness representations in single illnesses alone may miss important information about the impact of multimorbidity on representations of each individual condition, as well as missing information about the representations of multimorbidity itself (e.g., representations of the relationships between multiple illnesses). Importantly, research has recently begun to investigate illness representations in people with multiple illnesses. A qualitative study by Bower et al. (2012) explored multimorbid illness representations in people with at least two of five conditions: type 2 diabetes, chronic arthritis, chronic obstructive pulmonary disease, coronary heart disease, and depression. This study was one of the first to investigate what the content of illness representations might look like for people with multimorbidity. For individual conditions, several illness representation dimensions including identity, cause, consequences, and illness coherence, were found to be impacted by multimorbidity. For example, multimorbidity compounded the consequences experienced by participants, with difficulty in linking individual symptoms with a particular illness reducing coherence and impacting perceptions of identity and cause. Several dimensions relating to representations of

multimorbidity were also identified, including medication burden (the perceived burden of taking medications for multiple conditions), condition priority (the relative importance assigned to each condition), and management synergies and antagonisms (the perception that managing one condition may benefit or aggravate another condition). These three dimensions' impact how people self-manage their illnesses, and may be appropriate targets for intervention.

A qualitative study with participants who had co-morbid diabetes and depression by Mc Sharry, Bishop, Moss-Morris, and Kendrick (2013) emphasised the importance of understanding how people perceive the relationships between their illnesses, and provided further evidence for the existence of multimorbid illness representations that influence how illnesses are self-managed. Illnesses were either described as unrelated with separate management strategies used for each, or as related with interactions between each illness. For those who saw interactions between diabetes and depression, causal relationships were often perceived (e.g., diabetes as causing depression or depression as causing diabetes), with the nature of these relationships impacting the management of both illnesses. Further, either integrated or conflicting self-management strategies were described by people who perceived diabetes and depression as related. For example, symptoms of depression such as fatigue and apathy interfered with diabetes self-management strategies such as exercise. Similar to Bower et al. (2012) medication burden was highlighted as a concern for people with multimorbid conditions, with difficulties in self-management perhaps related to a failure in self-regulation caused by the high self-regulatory demands associated with multimorbidity (Detweiler-Bedell, Friedman, Leventhal, Miller, & Leventhal, 2008).

A systematic review by Alderson et al. (2012) aimed to examine people's beliefs about depression in the presence of a chronic physical illness. However, a systematic literature search only located two qualitative studies that examined beliefs about depression

associated with a chronic physical illness. Due to the paucity of research in this area, Alderson, Foy, Glidewell, and House (2014) later conducted a qualitative study of beliefs about depression in people with coronary heart disease and/or diabetes. They found that general beliefs about depression were unable to be separated from beliefs about depression related to diabetes or coronary heart disease, again highlighting the importance of multimorbid representations for understanding illness beliefs and designing interventions.

These qualitative studies (Alderson et al., 2014; Bower et al., 2012; Mc Sharry et al., 2013) support the existence of the CSMs illness representation dimensions (e.g., cause, consequences, coherence), with these studies also highlighting the existence of additional illness representations that are specific to multimorbidity. Such multimorbid representations are likely to vary for different combinations of illnesses (e.g., diabetes and depression versus cancer and depression), with this partially demonstrated by the findings of the studies described. Therefore, using the CSM (as the best existing framework) may help to gain a deeper understanding of, as well as provide additional insights into, the illness representations of people with cancer and anxiety/depression specifically. Representations may differ for people with this specific combination of illnesses for several reasons. For example, people with cancer experience varying cancer types, stages of disease progression, and treatment types, and these factors are very likely to influence representations of co-morbid anxiety/depression. Further, pharmacological treatments such as chemotherapy are associated with multiple side effects, while cancer-related surgery can affect issues such as body image. People with cancer also often experience fear of cancer recurrence (FCR), a unique form of anxiety experienced by cancer patients/survivors that comprises fears or worries about a return or progression of a previous or new cancer (Lee-Jones, Humphris, Dixon, & Hatcher, 1997; Simard, Savard, & Ivers, 2010). How FCR interacts with multimorbid representations, coping behaviours, and self-management strategies, may also provide important insights for

this population. Due to the unique issues associated with experiencing co-morbid cancer and anxiety/depression, as well as the lack of research into the experience of co-morbid cancer and anxiety/depression specifically, there is a need for more exploratory research to understand how people with this common combination of physical and mental illness make sense of their illnesses and associated difficulties (Study 3).

### **Comparing Support Needs across People with Cancer and Anxiety/Depression**

How a person experiences cancer and anxiety/depression can be markedly different based on their varying histories of each illness, with these varying aetiologies shown to cause significant differences in health outcomes (Angst, Gamma, Rössler, Ajdacic, & Klein, 2009). It follows that these variances are therefore highly likely to also cause differences in support needs for people with cancer and anxiety/depression. In order to facilitate a better understanding of how support needs might differ between people with cancer and anxiety/depression, a comparison of the support needs of people with cancer and different histories of anxiety/depression was required (Study 4).

In the field of psycho-oncology there is a common (mis)conception that anxiety/depression are a normal part of the cancer experience (Pasquini & Biondi, 2007). Unfortunately, this misconception has precluded appropriate treatment for anxiety/depression in people with cancer, with many cancer patients requiring yet not receiving adequate treatment (Nakash et al., 2014; Pasquini & Biondi, 2007; Sanjida et al., 2016). Despite this misconception, research has shown that people with cancer do not always develop anxiety/depression, with varying levels of distress experienced across cancer patients (Helgeson, Snyder, & Seltman, 2004; Henselmans, Helgeson, et al., 2010). Further, a person who is diagnosed with cancer may have a long-term pre-existing diagnosis of anxiety/depression or experience episodic anxiety/depression in response to significant life events. How such varying histories of anxiety/depression may influence the support needs of



people with cancer and anxiety/depression has rarely been considered across research in psycho-oncology.

Although the support needs of people with cancer have been extensively researched (Harrison, Young, Price, Butow, & Solomon, 2009), a recent review found that interventions aimed at reducing unmet supportive care needs in cancer patients have limited effectiveness (Carey et al., 2012). Further, interventions for cancer patients with distress rarely consider how a prior history of anxiety/depression may influence intervention effectiveness, and often provide mixed results and conflicting conclusions (Galway et al., 2012; Jacobsen & Jim, 2008; Lepore & Coyne, 2006). Examining and comparing the support needs of people with varying histories of cancer and anxiety/depression may therefore inform the creation of more appropriately focused and targeted interventions. Why support needs may differ between people with cancer and varying histories of anxiety/depression relates to the significant differences in health outcomes between people with long-term anxiety/depression and people with episodic anxiety/depression. For example, long-term depression has been found to require more treatment, be more clinically serious, be more often co-morbid with anxiety, and lead to reduced well-being and poorer social and psychological outcomes than episodic depression (Angst et al., 2009). In order to create more appropriate interventions and better support people with cancer and anxiety/depression, research should examine and compare the support needs of people who have cancer and long-term anxiety/depression and people who have cancer and episodic anxiety/depression (Study 4).

### **The Present Thesis**

The present thesis investigates the role of the Common Sense Model of Self-Regulation of Health and Illness (Leventhal et al., 1980) in understanding how people's representations of cancer and anxiety/depression influence their coping behaviours, self-management strategies, and illness outcomes, and what particular support needs people with

cancer and anxiety/depression express based on their understanding of their illnesses.

As highlighted above, cancer and anxiety/depression commonly occur as co-morbid conditions, leading to poor health and illness outcomes. However, too little is currently known about the psychological processes underlying this combination of illnesses. Chapter 2 presents a systematic review of the relationships between illness representations and coping behaviours and illness representations and illness outcomes in people with cancer. Chapter 3 presents a second systematic review of the relationships between illness representations and coping behaviours and illness representations and illness outcomes, but this time in people with depression. Chapter 4 examines the content of multimorbid illness representations and the relationship between these multimorbid representations and self-management strategies in people with cancer and anxiety/depression. Chapter 5 explores how support needs differ between people with long-term anxiety/depression and episodic anxiety/depression, as well as between people with anxiety/depression associated with cancer and anxiety/depression not associated with cancer. Chapter 6 concludes this thesis with an integrative discussion of the study findings, overall limitations, both theoretical and practical implications, and suggestions for future research.

*Study 1 (Chapter 2): Illness representations, coping, and illness outcomes in people with cancer: A systematic review and meta-analysis*

Aim: To provide a systematic overview of the relationships between the Common Sense Model's illness representations and health and coping outcomes in people with cancer.

Due to the large pool of existing literature examining the relationship between illness representations, coping behaviours, and illness outcomes in people with cancer, as well as the

inconsistency across some of these study findings, Study 1 involved the completion of a systematic review and meta-analysis to synthesise the existing literature and reach a consensus on the strength and direction of these relationships. A systematic literature search identified 54 studies meeting inclusion criteria, with 38 studies providing sufficient data to be included in the meta-analysis and the remaining 16 studies included in a narrative review.

*Study 2 (Chapter 3): Illness representations, coping, and illness outcomes in depression: A systematic review and meta-analysis*

Aim: To provide a systematic overview of the relationships between the Common Sense Model's illness representations and health and coping outcomes in people with depression.

Although clear relationships have been found between the CSMs illness representation dimensions and coping and outcomes in people with chronic physical illnesses, the ability of this model to explain relationships between illness beliefs and behaviour in people with mental illnesses is less well established, with no quantitative synthesis examining this relationship in people with depression specifically. Study 2 therefore involved the completion of a systematic review and meta-analysis to examine the relationships between illness representations, coping, and outcomes in people with depression. Nineteen studies were located following a systematic literature search, with 10 providing sufficient data for meta-analysis, and nine included in a narrative review.

*Study 3 (Chapter 4): 'It was all intertwined': Illness representations and self-management in people with cancer and anxiety/depression*

Aim: To explore the content of individual's multimorbid representations of cancer and anxiety/depression, as well as how these relate to their coping behaviours and self-management strategies.

Though well established in single chronic illnesses, research has only recently begun to investigate the content and role of illness representations in people with multiple illnesses, with research yet to examine the illness representations of people with co-morbid cancer and anxiety/depression. Study 3 aimed to address this gap in existing literature by qualitatively examining the nature of illness representations for both cancer and anxiety/depression, whether all individuals think about the relationships between cancer and anxiety/depression in similar ways, and how particular illness representations might facilitate different coping behaviours or self-management strategies for cancer and anxiety/depression. To examine these aims, 21 semi-structured face-to-face interviews were conducted, and a theoretical thematic analysis provides a detailed analysis of differences in representations between those who identified links between cancer and anxiety/depression and those that did not.

*Study 4 (Chapter 5): A qualitative comparison of the support needs of people with cancer based on their history of anxiety/depression*

Aim: To examine and compare the support needs of people with cancer and varying histories of anxiety/depression in order to provide suggestions for improvements in support and service provision.

The field of psycho-oncology (both in research and in practice) rarely takes into account the origin and history of anxiety/depression in a person with cancer, instead

assuming it to be related to the cancer diagnosis. In order to determine whether and how this history may influence the support needs of people with cancer and anxiety/depression, interview transcripts from 21 people (same participant pool as Study 3) were analysed (Study 4). Study 4 categorised participants into four groups based on their history of anxiety/depression, specifically considering whether they had experienced long-term anxiety/depression or episodic anxiety/depression, as well as whether they had experienced anxiety/depression that was associated with their cancer diagnosis or anxiety/depression that was not associated with their cancer diagnosis. Following categorisation, an inductive thematic analysis was used to collate codes into relevant themes and highlight important differences between groups.

## **Chapter 2**

### **Study 1**

#### **Illness representations, coping, and illness outcomes in people with cancer: A systematic review and meta-analysis\***

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\*Richardson, E. M., Schüz, N., Sanderson, K., Scott, J. L., Schüz, B. (2016). Illness representations, coping, and illness outcomes in people with cancer: A systematic review and meta-analysis. *Psycho-Oncology*. Advance online publication. doi: 10.1002/pon.4213 (see Appendix 2.1)

## Abstract

**Objective:** Cancer is associated with negative health and emotional outcomes in those affected by it, suggesting the need to better understand the psychosocial determinants of illness outcomes and coping. The Common Sense Model (CSM) is the leading psychological model of self-regulation in the face of illness, and assumes that subjective illness representations explain how people attempt to cope with illness. This systematic review and meta-analysis examines the associations of the CSM's illness representation dimensions with health and coping outcomes in people with cancer.

**Methods:** A systematic literature search located 54 studies fulfilling the inclusion criteria, with 38 providing sufficient data for meta-analysis. A narrative review of remaining studies was also conducted.

**Results:** Random-effects models revealed small to moderate effect sizes (Fischer's Z) for the relations between illness representations and coping behaviours (in particular between control perceptions, problem-focused coping, and cognitive reappraisal), and moderate to large effect sizes between illness representations and illness outcomes (in particular between identity, consequences, emotional representations, and psychological distress). The narrative review of studies with insufficient data provided similar results.

**Conclusions:** The results indicate how illness representations relate to illness outcomes in people with cancer. However, more high quality studies are needed to examine causal effects of illness representations on coping and outcomes. High heterogeneity indicates potential moderators of the relationships between illness representations and health and coping outcomes, including diagnostic, prognostic, and treatment related variables. This review can inform the design of interventions to improve coping strategies and mental health outcomes in people with cancer.

**Keywords:** cancer; oncology; illness perceptions; common sense model of illness representations; systematic review and meta-analysis

## Background

Cancer is one of the most prevalent diseases worldwide, with more than 14 million new cancer cases diagnosed annually (International Agency for Research on Cancer & World Health Organisation, 2014). Often, people with cancer experience negative health outcomes (e.g., anxiety, depression, psychological distress, poor role/physical functioning, and reduced quality of life) and face extraordinary coping challenges (Croom, Hamann, & Kehoe, 2013; Deimling et al., 2006; Edwards & Clarke, 2004; Harrington et al., 2010; O'Brien & Moorey, 2010; Singer et al., 2010). These outcomes and coping behaviours depend on individual representations of illness (Diefenbach & Leventhal, 1996), but to date, no systematic review and meta-analysis has provided an overview of the complex relationships between illness representations, coping and illness outcomes in cancer to inform the content of psychological interventions based on subjective illness representations.

### Illness Representations and the Common Sense Model

The Common Sense Model of Self-Regulation of Health and Illness (CSM; Leventhal et al., 1980) is a widely accepted psychological model of the processes underlying health and coping in people with chronic illness. According to the CSM, individual representations of health threats (i.e., people's common-sense understanding of their illness; Leventhal et al., 1998; Leventhal et al., 1980) and the according emotional response guide peoples' coping responses in parallel processes, which are later appraised in terms of their success or failure (Diefenbach & Leventhal, 1996) (Figure 2.1).

The CSM orders illness representations into distinct dimensions. *Identity* refers to the label of the health threat (e.g. cancer) and its symptoms (e.g. fatigue). *Cause* refers to the individual's beliefs about the cause of the health threat (e.g. genetic weakness). *Timeline* refers to the perceived time-frame of disease development, duration, and recovery (e.g. acute, chronic, or cyclical). *Consequences* (both imagined and real) are beliefs about what effect the



health threat may have on an individual's life (e.g. absence from work). *Curability* or *controllability* refers to the degree to which someone believes that the health threat can be controlled or cured by themselves or others (e.g. incurable but controllable with medication) (Leventhal et al., 1998). This dimension has later been revised to represent two distinct dimensions - *personal control* - the amount of control an individual perceives to have over the course of their illness, and *treatment control* - the amount of control the individual believes their treatment has over the illness. *Illness coherence* refers to the extent to which a patient's illness representations provide coherent understanding of the illness, and *emotional representations* describe an individual's emotional responses to the illness (Moss-Morris et al., 2002). The most widely used instruments to assess illness representations are the Illness Perception Questionnaire (IPQ; Weinman et al., 1996), the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002), and the Brief Illness Perception Questionnaire (B-IPQ; Broadbent et al., 2006). The IPQ-R has acceptable test-retest reliability, sound discriminant and predictive validity, and good internal reliability (Moss-Morris et al., 2002).

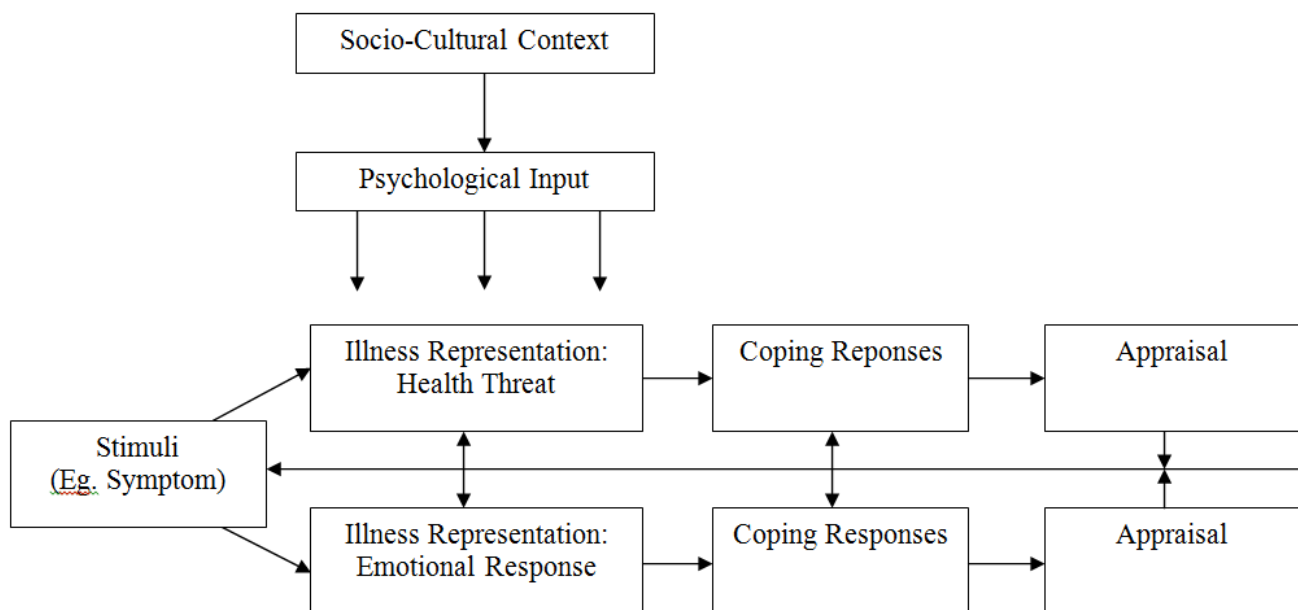


Figure 2.1. The common sense model of self-regulation of health and illness (Leventhal et al., 1980), adapted from Diefenbach and Leventhal (1996).

In a seminal systematic review of the CSM, Hagger and Orbell (2003) have shown that the IPQ dimensions are related to both coping behaviours (such as avoidance/denial and medication adherence) and illness outcomes (e.g., depression and physical functioning) across a range of chronic and acute illnesses. In particular, greater perceived controllability was associated with more adaptive coping strategies, while perceiving an illness as highly symptomatic with a chronic timeline and serious consequences was associated with more maladaptive coping strategies. Perceptions of the illness as curable and controllable were associated with positive illness outcomes, while perceived negative consequences, chronic timeline, and higher identity (more perceived symptoms) were associated with negative illness outcomes. These relations highlight the importance of subjective representations for understanding how people cope with illness and their illness outcomes. However, the review by Hagger and Orbell (2003) included only one study of cancer patients. Further, in the 13 years since this original review, the number of publications examining illness representations in cancer have greatly increased.

### **Illness Representations in Cancer: The Present Review**

Illness representations might be particularly relevant to understanding coping and illness outcomes in the area of cancer, as people hold strong and readily accessible representations of cancer based on common-sense knowledge (Anagnostopoulos & Spanea, 2005; Buick & Petrie, 2002). These representations determine coping and illness outcomes, for example higher levels of control and better understanding have been associated with lower rates of anxiety and depression (Dempster et al., 2012).

However, the size (and occasionally direction) of these associations varies across studies, with one study finding a moderate negative relationship between illness coherence and anxiety (Keeling et al., 2013), whereas another study found a negligible positive relationship between illness coherence and anxiety (Freeman-Gibb, 2012). Such inconsistent

findings warrant a systematic review to determine a consensus on the strength and direction of the relationships between illness representations and health and coping outcomes.

The findings of this review have the potential to inform clinical interventions based on illness representations. Some previous intervention studies in other chronic illness patients (e.g., Siemonsma et al., 2013) support the malleability of coping behaviours and illness outcomes via modifying illness representations, although to date, none have been conducted with cancer patients.

### **Aims and Hypotheses**

The present review aims to provide the first systematic overview of the relationships between illness representations and health and coping outcomes in people with cancer. Consistent with the findings from Hagger and Orbell (2003) involving diverse chronic illnesses, we hypothesised that higher identity, acute/chronic timeline, cyclical timeline, consequences, and emotional representations, as well as lower personal control, treatment control, and illness coherence, would be associated with more maladaptive coping behaviours (e.g., higher levels of avoidance/denial) and more negative illness outcomes (e.g., higher levels of anxiety). In contrast, lower identity, acute/chronic timeline, cyclical timeline, consequences, and emotional representations, as well as higher personal control, treatment control, and illness coherence, were predicted to be associated with more adaptive coping behaviours (e.g., higher levels of cognitive reappraisal) and more positive illness outcomes (e.g., higher quality of life).

## **Methods**

### **Literature Search, Inclusion Criteria, and Study Selection**

This study followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Statement (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009; Appendix 2.2), with no ethical approval required. A systematic literature search was

conducted using *Scopus*, *Web of Science*, *PubMed*, *PsycINFO*, and *CINAHL*. In an attempt to locate ‘grey literature’ additional searches were conducted through *Google Scholar*. For the full search strategy for each database refer to Appendix 2.3. A manual search of the reference lists of included articles was also completed to identify additional studies. Attempts were made to locate missing data sets by contacting relevant authors.

Studies were eligible for inclusion if they met the following criteria: quantitative design, including any subscale from the IPQ (Weinman et al., 1996), the IPQ-R (Moss-Morris et al., 2002), or the B-IPQ (Broadbent et al., 2006), measuring coping behaviours or illness outcomes, adult participants (over 18 years) with a cancer diagnosis, written in English or German, and conducted after 1995 (post IPQ development).

Following three consecutive literature searches and full-text coding by the first author (using a coding manual and coding sheet: see Appendix 2.4 and Appendix 2.5), the final number of studies for the systematic review was 54, with 38 included in the meta-analysis (based on relevant data) (Beatty & Scott, 2013; Cameron et al., 2005; Chen, 2012; Cook et al., 2015a; Corter, Findlay, Broom, Porter, & Petrie, 2013; Costanzo, Lutgendorf, & Roeder, 2011; Croom, 2012; Croom et al., 2013; Dempster et al., 2012; Donovan, 2003; Duric et al., 2007; S. Y. Fan, Eiser, Ho, & Lin, 2013; Fischer et al., 2013; Förster & Taubert, 2006; Foster et al., 2015; Freeman-Gibb, 2012; A. Gibbons, 2013; Gould et al., 2010; Green, Steinnagel, Morris, & Laakso, 2014; Henselmans, Sanderman, et al., 2010; Hopman & Rijken, 2014; Karademas & Giannousi, 2013; Keeling et al., 2013; Llewellyn, McGurk, & Weinman, 2006, 2007b; Llewellyn, Weinman, McGurk, & Humphris, 2008; McCorry et al., 2013; Mols, Lemmens, Bosscha, van den Broek, & Thong, 2014; Paschali, Hadjulis, Papadimitriou, & Karademas, 2015; Rozema, Völlink, & Lechner, 2009; Scharloo et al., 2010; Silva, Moreira, & Canavarro, 2012; Thuné-Boyle, Myers, & Newman, 2006; Traeger, 2009; Traeger et al., 2009; van der Kloot et al., 2014; Wu, Mohamed, Winkel, & Diefenbach, 2013; Zivkovic,

Buljan, Blajic, & Situm, 2008). A flow-chart of the study selection process can be found in Figure 2.2, with a detailed description of the search process in Appendix 2.6.

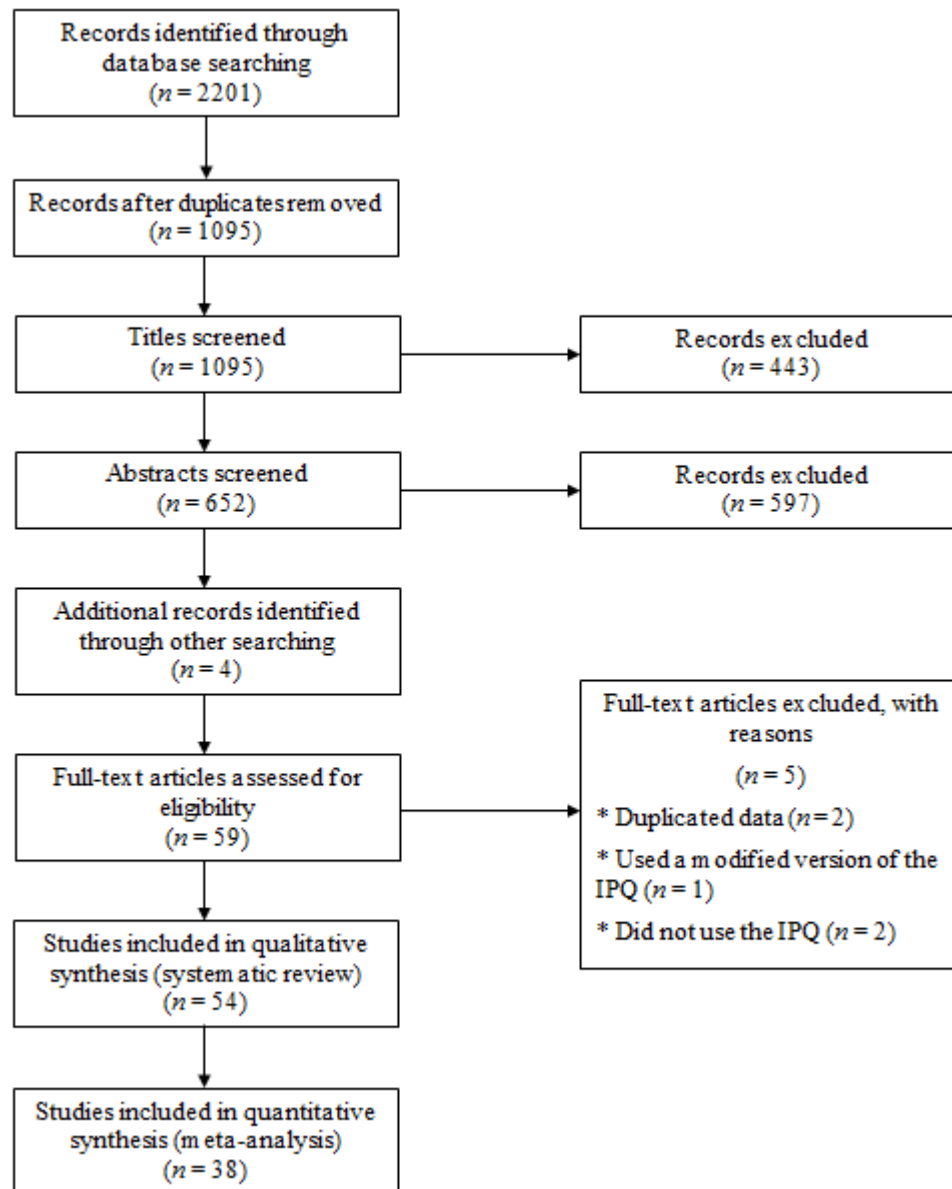


Figure 2.2. Flow-chart of the study selection process.

### Classification of Coping Behaviours and Illness Outcomes

Categories of coping behaviours were adapted from Hagger and Orbell (2003) to include the behaviours most frequently mentioned in the cancer literature. Eleven categories

were identified: expressing emotion, cognitive reappraisal, avoidance/denial, problem-focused coping (generic and specific behaviours separately), treatment decision making, medication adherence, adherence to treatment visits, doctor visits, seeking social support, and other (specified) coping behaviour. Only three of these categories (cognitive reappraisal, avoidance/denial, and problem-focused coping [generic]) could be used in the meta-analysis due to a lack of studies measuring or reporting the other categories.

Illness outcomes were also classified using the categories in Hagger and Orbell (2003) and extended if necessary. Thirteen categories were identified: affect (negative/positive), anxiety, depression, psychological distress, treatment related distress, decisional uncertainty/regret, psychological well-being, vitality, role functioning, physical functioning, disease state, quality of life, and other (specified) illness outcome. Only seven of these categories (anxiety, depression, psychological distress, psychological well-being, role functioning, physical functioning, and quality of life) were used in the meta-analysis due to a lack of studies measuring or reporting the other categories.

### **Data Extraction and Meta-Analytic Strategy**

We extracted publication date, cancer type, sample characteristics (age and sex), study design, IPQ version, coping behaviours, illness outcomes, and a summary of the relevant results from all identified articles (Appendix 2.7 shows a summary of studies included in the meta-analysis; Appendix 2.8 shows a summary of studies included in the narrative review).

To assist in evaluating validity of results, risk of bias was assessed using four criteria relevant to the research aims: (i) whether each version of the IPQ had been administered as recommended; (ii) which IPQ dimensions were reported; (iii) whether equivalent correlational analyses were conducted across studies; (iv) whether adjustments were made for confounding variables.

Zero-order correlations were the most frequently reported effect size, and therefore

the average correlation coefficient weighted by sample size and calculated using Fischer's  $Z$  transformations ( $r_z$ ) was used as the measure of effect in the meta-analysis. We interpreted .10 as a small effect, .30 as a moderate effect, and .50 as a large effect (Cohen, 1992). The meta-analyses were conducted in R (R Core Team, 2014) using the 'metafor' package (Viechtbauer, 2010). A random-effects meta-analysis was performed, which accommodates the assumption that the true effect size (the effect size in the underlying population of studies) may vary from study to study due to heterogeneity (Borenstein, Hedges, Higgins, & Rothstein, 2010). In the present meta-analysis, the studies were likely to be heterogeneous due to differing study designs, cancer types, treatment types, and other sampling characteristics.

To examine heterogeneity between studies,  $Q$  and  $I^2$  statistics were calculated. To assess publication bias ('file drawer problem'), funnel plots and the 'fail-safe N' ( $N_{fs}$ ) were examined, and moderator analyses (random-effects meta-regression) were conducted as appropriate. In these analyses, cross-sectional (0) and longitudinal (1) design were entered as predictors of the effect sizes between studies, and  $B$ 's can be interpreted as differences in the pooled effect sizes between cross-sectional and longitudinal studies. For additional information regarding the meta-analytic strategy used in our review, please refer to Appendix 2.9.

## Results

### Study Characteristics

Thirty-six (66.67%) of the studies had a cross-sectional design, two (3.70%) were experimental with only baseline correlations extracted, and 16 (29.63%) were longitudinal with intervals ranging from one week to twelve months. Sample sizes ranged between 43 and 1019, with a mean sample size of 182. Eleven different types of cancer were reported, with the most common breast cancer (15 studies, 27.78%), followed by head and neck cancer

(seven studies, 12.96%), and prostate cancer (six studies, 11.11%). Sixteen studies (29.63%) reported heterogeneous cancer populations (multiple cancer types) and were classified as ‘not specified’. Other cancer types included colorectal, oesophageal, gynaecological, oral, ovarian, liver, brain, and skin. Cancer stage was coded, but only 19 of 38 studies (50%) in the meta-analysis provided data on participants’ cancer stage, which additionally was often based on different staging systems (e.g., TNM, idiosyncratic systems) with no separate results provided for differing cancer stages. In 27 studies (50% of all articles reviewed), the IPQ was adapted to be ‘cancer specific’, rather than using the generic version. This involved minor changes in wording and the inclusion of cancer specific symptoms and causes. For more key study characteristics refer to Appendix 2.7 and Appendix 2.8.

### **Risk of Bias Assessment**

Risk of bias assessment was based on the fidelity of measurement of illness representations and outcomes as well as study design. The majority of studies (42 out of 54) administered the IPQ, IPQ-R, or B-IPQ as recommended, with some studies (12 out of 54) only partially adhering to guidelines by developers. Those studies either used shortened versions of subscales, added items to subscales, or adapted items to suit the sample or cancer patients specifically. Most studies reported the correlations of the illness representation dimensions they had assessed, with those that did not contacted for missing data. However, data was unable to be obtained for three studies omitting cause and three that failed to report non-significant results. In 30 out of 38 studies Pearson’s correlation coefficients were reported, with Spearman’s correlation coefficients used in two, lagged, point-biserial, and bivariate used in one each, and three studies not specifying a correlation type. Four studies adjusted for either demographic or cancer-specific confounding variables (Croom, 2012; Gould et al., 2010; van der Kloot et al., 2014; Wu et al., 2013), see Appendix 2.10.

### **Relationship of Illness Representations to Coping Behaviours: Quantitative Analysis**



Table 2.1 shows that the relations between coherence, cyclical timeline, consequences, emotional representations and avoidance/denial, and the relations between identity, acute/chronic timeline and generic problem-focused coping, were subject to high heterogeneity, with the remaining  $I^2$  values indicating moderate-low heterogeneity between studies.

The majority of results from the meta-analyses between coping behaviours and illness representations indicate small to moderate effects (Table 2.1, Forest plots in Appendix 2.11).

***Cognitive reappraisal.*** The strongest correlate of cognitive reappraisal was personal control, with higher levels of control associated with higher levels of cognitive reappraisal. Other correlates included acute/chronic timeline, emotional representations, and treatment control.

***Avoidance/denial.*** The strongest correlate of avoidance/denial was emotional representations, with higher levels of emotional representations associated with higher levels of avoidance. The other key correlate of avoidance/denial was cyclical timeline.

***Problem focused coping (generic).*** The strongest correlate of problem-focused coping (generic) was personal control, with higher levels of control associated with higher levels of problem-focused coping. The other key correlate of problem-focused coping (generic) was consequences.

#### **Publication bias: Funnel plots and fail-safe N.**

Across all relationships between illness representations and coping behaviours, funnel plots (Appendix 2.12) were generally symmetrical. Although some funnel plots were skewed, it has been recommended that these plots be interpreted with caution, as any skew in the funnel may be explained by considerable heterogeneity amongst studies, indicating that publication bias is unlikely (Lau, Ioannidis, Terrin, Schmid, & Olkin, 2006). Fail-safe N was

Table 2.1

*Meta-Analyses of the Relationships between Illness Representations and Coping Behaviours*

Illness-Representation	Cognitive-Reappraisal							Avoidance/Denial							Problem-Focused-Coping-(Generic)						
	<i>k</i>	<i>N</i>	$r_z$	(95%CI)	$N_{fs}$	<i>Q</i>	$I^2$	<i>k</i>	<i>N</i>	$r_z$	(95%CI)	$N_{fs}$	<i>Q</i>	$I^2$	<i>k</i>	<i>N</i>	$r_z$	(95%CI)	$N_{fs}$	<i>Q</i>	$I^2$
Identity	4	351	.019	(-.141, .179)	0	6.54	54.38	5	470	.022	(-.125, .169)	0	10.15*	59.96	5	1008	.068	(-.092, .229)	14	25.78***	76.71
Cause								6	832	.075*	(.006, .144)	2	4.02	<.01	4	1004	-.031	(-.093, .031)	0	.15	<.01
Timeline-(Acute/Chronic)	7	809	-.201**	(-.341, -.062)	66	21.02**	72.67	9	1033	.049	(-.076, .174)	0	28.55***	73.86	8	1298	.026	(-.110, .162)	0	30.90***	78.73
Timeline-(Cyclical)	6	650	.024	(-.064, .111)	0	5.72	15.90	8	874	.217**	(.060, .373)	94	31.34***	80.20	7	1141	.054	(-.053, .161)	4	15.25*	57.11
Consequences	7	732	-.036	(-.135, .064)	0	10.78	40.16	8	879	.130	(-.010, .270)	26	27.45***	75.46	7	1151	.121*	(.013, .229)	32	13.44*	58.01
Personal-Control	7	811	.287***	(.182, .391)	151	12.21	51.35	10	1146	-.005	(-.082, .072)	0	14.68	38.17	7	673	.286***	(.178, .394)	128	11.62	47.58
Treatment-Control	5	572	.183*	(.014, .352)	27	13.46**	72.47	7	797	-.025	(-.126, .075)	0	10.90	46.39	5	435	-.007	(-.194, .179)	0	12.87*	72.70
Illness-Coherence	6	650	.104**	(.026, .182)	10	5.22	.02	7	755	-.170	(-.382, .042)	39	44.09***	87.48	6	1029	.082*	(.002, .163)	7	5.90	20.77
Emotional-Representations	5	589	-.190***	(-.272, -.108)	34	3.98	.01	8	923	.240**	(.073, .406)	121	41.06***	83.75	6	1270	-.046	(-.160, .069)	0	13.17*	68.04

Note. *k* = number of studies, *N* = total sample size across included studies,  $r_z$  = effect size, (95%CI) = 95% confidence intervals around the effect size,  $N_{fs}$  = Rosenthal's fail-safe N (measure of publication bias),

*Q* = measure of heterogeneity (suggests heterogeneity when statistically significant),  $I^2$  = measure of heterogeneity (25% = low, 50% = moderate, 75% = high)

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

found to range from zero to 151 across the relationships between illness representations and coping behaviours (Table 2.1).

### **Relationship of Illness Representations to Illness Outcomes: Quantitative Analysis**

High heterogeneity was observed in studies examining psychological distress and emotional representations; role functioning and illness coherence; physical functioning and identity, consequences, coherence, and emotional representations; and quality of life and identity, treatment control, and illness coherence. Overall, there was a wide range of effect sizes of the associations between illness outcomes and illness representations, from negligible effects to very large effects (Tables 2.2, 2.3, and 2.4).

**Anxiety.** The strongest correlate of anxiety was emotional representations, with higher emotional representations associated with higher anxiety. Other moderate-strong correlates included consequences, identity, cyclical timeline, and acute/chronic timeline.

**Depression.** The strongest correlate of depression was emotional representations, with higher emotional representations associated with more depression. Other moderate-strong correlates included identity, consequences, cyclical timeline, treatment control, and acute/chronic timeline. Table 2.2 contains the full set of analyses regarding anxiety and depression; forest plots can be found in Appendix 2.11.

**Psychological distress.** Emotional representations were the highest correlate of psychological distress, with higher emotional representations associated with more distress. Other moderate to strong correlates included consequences, identity, cyclical timeline, and acute/chronic timeline.

**Psychological well-being.** The strongest correlate of psychological well-being was consequences, with less consequences associated with more psychological well-being. Table 2.3 contains all analyses regarding psychological distress and well-being; forest plots are shown in Appendix 2.11.

***Role functioning.*** The strongest correlate of role functioning was identity, with lower identity scores (perceived cancer related symptoms) associated with better role functioning. Other correlates included emotional representations, and consequences.

***Physical functioning.*** The strongest correlate of physical functioning was identity, with lower identity scores associated with better physical functioning. Other correlates included consequences, emotional representations, acute/chronic timeline, and treatment control.

***Quality of life.*** The strongest correlate of quality of life was identity, with lower identity scores associated with better quality of life. Other moderate to strong correlates included consequences, emotional representations, and acute/chronic timeline. Table 2.4 contains all analyses regarding role functioning, physical functioning, and quality of life; forest plots are shown in Appendix 2.11.

#### **Illness outcomes and publication bias: Funnel plots and fail-safe N.**

Across the relationships, funnel plots (Appendix 2.12) were generally symmetrical, although this was difficult to assess in plots with small numbers of studies. The number of studies that fell outside the funnel generally varied between none and three, with one plot displaying four points outside the funnel (psychological distress and illness coherence). Across the relationships between illness representations and illness outcomes the fail-safe N ranged from zero to 3975. The two relationships with a fail-safe N of zero (illness coherence and physical functioning; illness coherence and quality of life) both also had high heterogeneity, suggesting the presence of moderators (Card, 2012).

#### **Moderator Analyses**

##### **Study-level moderators.**

We examined whether research design (cross-sectional versus longitudinal) affected the effect sizes (correlations between illness representations and coping as well as outcomes)

Table 2.2

*Meta-Analyses of the Relationships between Illness Representations and Anxiety, and Illness Representations and Depression*

Illness-Representation	Anxiety							Depression						
	<i>k</i>	<i>N</i>	$r_z$	(95%CI)	$N_{fs}$	<i>Q</i>	$I^2$	<i>k</i>	<i>N</i>	$r_z$	(95%CI)	$N_{fs}$	<i>Q</i>	$I^2$
Identity	10	1782	.360***	(.295,.426)	702	14.53	39.95	9	1615	.470***	(.392,.549)	977	17.18*	51.73
Cause	6	1236	.163**	(.067,.259)	54	14.14*	59.91	6	1158	.106**	(.032,.180)	21	6.52	29.89
Timeline-(Acute/Chronic)	12	2524	.259***	(.185,.333)	619	32.09***	67.18	10	2166	.260***	(.179,.341)	433	24.88**	67.56
Timeline-(Cyclical)	10	1556	.289***	(.208,.371)	406	19.58*	56.28	7	1148	.272***	(.175,.370)	173	12.96*	56.04
Consequences	15	2777	.443***	(.374,.512)	2548	38.96***	65.38	13	2388	.416***	(.353,.479)	1643	23.90*	49.66
Personal-Control	16	2922	-.119***	(-.170,-.068)	192	27.19*	4.73	13	2503	-.195***	(-.234,-.155)	369	9.62	.05
Treatment-Control	11	2441	-.192***	(-.240,-.144)	308	11.77	24.16	8	1942	-.261***	(-.308,-.215)	350	7.59	4.79
Illness-Coherence	13	2610	-.205***	(-.285,-.125)	425	39.54***	73.02	9	2039	-.155***	(-.236,-.074)	128	23.75**	64.87
Emotional-Representations	11	2083	.738***	(.652,.824)	3975	28.52**	71.05	8	1574	.517***	(.468,.567)	1064	11.04	.01

*Note.* *k* = number of studies, *N* = total sample size across included studies,  $r_z$  = effect size, (95%CI) = 95% confidence intervals around the effect size,  $N_{fs}$  = Rosenthal's fail-safe N (measure of publication bias), *Q* = measure of heterogeneity (suggests heterogeneity when statistically significant),  $I^2$  = measure of heterogeneity (25% = low, 50% = moderate, 75% = high)

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Table 2.3

*Meta-Analyses of the Relationships between Illness Representations and Psychological Distress, and Consequences and Psychological Well-being*

Illness-Representation	Psychological-Distress							Psychological-Well-Being						
	<i>k</i>	<i>N</i>	<i>r<sub>z</sub></i>	(95%CI)	<i>N<sub>fs</sub></i>	<i>Q</i>	<i>I<sup>2</sup></i>	<i>k</i>	<i>N</i>	<i>r<sub>z</sub></i>	(95%CI)	<i>N<sub>fs</sub></i>	<i>Q</i>	<i>I<sup>2</sup></i>
Identity	8	1555	.354***	(.268,.441)	471	15.74*	58.37							
Cause	6	1030	.174***	(.086,.261)	61	9.81	47.92							
Timeline-(Acute/Chronic)	8	1692	.185***	(.137,.233)	140	8.75	.01							
Timeline-(Cyclical)	5	735	.249***	(.103,.395)	69	11.34*	71.40							
Consequences	11	2287	.377***	(.336,.418)	1127	10.84	.01	4	956	-.355***	(-.419,-.291)	135	2.71	.01
Personal-Control	9	1921	-.091**	(-.158,-.023)	35	15.56*	48.02							
Treatment-Control	9	1908	-.130***	(-.205,-.055)	88	18.31*	57.83							
Illness-Coherence	9	1979	-.172***	(-.266,-.078)	146	29.45***	74.61							
Emotional-Representations	9	2003	.596***	(.496,.696)	2010	34.30**	77.50							

*Note.* *k* = number of studies, *N* = total sample size across included studies, *r<sub>z</sub>* = effect size, (95%CI) = 95% confidence intervals around the effect size, *N<sub>fs</sub>* = Rosenthal's fail-safe N (measure of publication bias), *Q* = measure of heterogeneity (suggests heterogeneity when statistically significant), *I<sup>2</sup>* = measure of heterogeneity (25% = low, 50% = moderate, 75% = high)

\**p* < .05, \*\**p* < .01, \*\*\**p* < .001

Table 2.4

*Meta-Analyses of the Relationships between Illness Representations and Role Functioning, Illness Representations and Physical Functioning, and Illness Representations and Quality of Life*

Illness-Representation	Role-Functioning							Physical-Functioning							Quality-of-Life						
	<i>k</i>	<i>N</i>	<i>r<sub>z</sub></i>	(95%CI)	<i>N<sub>fs</sub></i>	<i>Q</i>	<i>I<sup>2</sup></i>	<i>k</i>	<i>N</i>	<i>r<sub>z</sub></i>	(95%CI)	<i>N<sub>fs</sub></i>	<i>Q</i>	<i>I<sup>2</sup></i>	<i>k</i>	<i>N</i>	<i>r<sub>z</sub></i>	(95%CI)	<i>N<sub>fs</sub></i>	<i>Q</i>	<i>I<sup>2</sup></i>
Identity	4	1124	-.309***	(-.384,-.235)	136	3.56	28.14	4	1171	-.505***	(-.676,-.335)	350	19.57***	86.94	6	1289	-.607***	(-.772,-.443)	808	31.04***	86.22
Cause																					
Timeline-(Acute/Chronic)	4	1104	-.108***	(-.167,-.049)	11	.60	<.01	6	1323	-.265***	(-.378,-.152)	164	15.01*	72.11	8	1478	-.176***	(-.241,-.112)	97	7.13	24.95
Timeline-(Cyclical)								4	439	-.347***	(-.442,-.252)	74	1.44	<.01							
Consequences	7	1689	-.184***	(-.272,-.096)	133	18.17**	65.58	8	1693	-.367***	(-.481,-.253)	595	28.10***	79.30	8	1621	-.445***	(-.530,-.360)	800	16.61*	58.80
Personal-Control	6	1462	.072**	(.021,.124)	5	8.50	.01	6	1334	.118**	(.042,.194)	32	8.43	39.89	8	1509	.122**	(.042,.203)	50	13.92	50.91
Treatment-Control	5	1320	.088**	(.034,.143)	10	1.91	<.01	5	1244	.178***	(.078,.277)	63	9.59*	62.27	7	1337	.130*	(.007,.254)	63	22.64***	75.83
Illness-Coherence	5	1346	-.069	(-.269,.132)	10	56.94***	91.88	5	1232	-.006	(-.179,.167)	0	38.13***	87.20	6	1296	.043	(-.182,.267)	0	85.81***	92.84
Emotional-Representations	4	1132	-.292***	(-.350,-.233)	116	3.51	.09	7	1637	-.205***	(-.312,-.099)	176	19.73**	75.80	7	1539	-.426***	(-.501,-.351)	592	9.89	44.93

*Note.* *k* = number of studies, *N* = total sample size across included studies, *r<sub>z</sub>* = effect size, (95%CI) = 95% confidence intervals around the effect size, *N<sub>fs</sub>* = Rosenthal's fail-safe N (measure of publication bias), *Q* = measure of heterogeneity (suggests heterogeneity when statistically significant), *I<sup>2</sup>* = measure of heterogeneity (25% = low, 50% = moderate, 75% = high)

\**p* < .05, \*\**p* < .01, \*\*\**p* < .001

in random-effects meta-regressions. Most meta-regressions indicated non-significant and negligible moderator effects of study design. However, relationships between depression and identity ( $B = -.15$ ), acute/chronic timeline ( $B = -.18$ ), and consequences ( $B = -.15$ ) were significantly smaller in longitudinal studies. The same pattern of significantly smaller effect sizes in longitudinal studies was also found for the relationships between psychological distress and emotional representations ( $B = -.29$ ) as well as treatment control ( $B = .16$ ; note that the pooled correlation in this case was negative, thus the positive  $B$  indicates smaller effects), and between anxiety and acute/chronic timeline ( $B = -.17$ ). Overall, though smaller in effect, these findings suggest that relationships between illness representations, illness outcomes and coping behaviours were mostly stable overtime.

### **Relationship of Illness Representations to Coping Behaviours: Narrative Review**

A narrative review was conducted for the 16 studies where data required for quantitative meta-analysis could not be obtained (see Appendix 2.8 for a summary of study characteristics). There were five studies (Grande, Arnott, Brundle, & Pilling, 2014; Grande, Myers, & Sutton, 2006; Iskandarsyah, Klerk, Suardi, Sadarjoen, & Passchier, 2014; Landers, McCarthy, Livingstone, & Savage, 2014; Llewellyn, McGurk, & Weinman, 2007a) that examined coping behaviours, four of which (Grande et al., 2014; Grande et al., 2006; Iskandarsyah et al., 2014; Landers et al., 2014) focused on problem-focused coping via specific behaviours. The results of these studies are in line with the meta-analysis findings, with higher personal control associated with positive outcomes from participating in a cancer community support group (Grande et al., 2006), particularly in combination with higher emotional representations (Grande et al., 2014; Grande et al., 2006). More mixed results emerged for illness representations capturing negative consequences of illness; with higher identity scores and cyclical timeline related to better medication adherence (Landers et al., 2014), while women with more negative illness representations (or a more negative view of



their breast cancer) were more likely to miss treatment sessions (Iskandarsyah et al., 2014). This mixed pattern is perhaps most evident in (Llewellyn et al., 2007a), where several coping strategies were associated with each illness representation, for example higher perceived consequences of cancer and lower levels of illness coherence (understanding) were associated with higher levels of avoidance coping.

### **Relationship of Illness Representations to Illness Outcomes: Narrative Review**

Eleven of the 16 studies not included in the meta-analysis examined illness outcomes (Cook et al., 2015b; Cooper, Hankins, Rixon, Eaton, & Grunfeld, 2013; Dempster et al., 2011; Giannousi, Manaras, Georgoulas, & Samonis, 2010; Gray et al., 2014; Gray et al., 2011; Jørgensen, Frederiksen, Boesen, Elsass, & Johansen, 2009; Mickevičiune, Vanagas, Jievaltas, & Ulys, 2013; Millar, Purushotham, McLatchie, George, & Murray, 2005; Scharloo et al., 2005; Traeger et al., 2013), along with one study examining both illness outcomes and coping behaviours (Llewellyn et al., 2007a). These findings were also largely in line with the results of the quantitative meta-analysis. Poor role functioning was associated with a perception of more negative consequences of cancer, less perceived personal control over cancer, and more perceived cancer symptoms (Cooper et al., 2013; Scharloo et al., 2005). Higher levels of anxiety were associated with less perceived personal and treatment control over cancer, a greater emotional impact of cancer (higher emotional representations), and more severe consequences of cancer (Cook et al., 2015b; Dempster et al., 2011; Gray et al., 2014). Similarly, higher levels of depression were associated with less perceived personal and treatment control over cancer, a greater emotional impact of cancer, more severe consequences of cancer, as well as a more chronic perceived timeline of cancer (Dempster et al., 2011; Giannousi et al., 2010; Gray et al., 2014; Llewellyn et al., 2007a). As expected, higher levels of psychological distress were also associated with a greater emotional impact of cancer, more severe consequences of cancer, a more chronic perceived timeline of cancer,

as well as more perceived cancer symptoms (Jørgensen et al., 2009; Mickevičiene et al., 2013; Millar et al., 2005). Finally, a better quality of life was associated with less perceived cancer symptoms, a less cyclical timeline, less severe consequences of cancer, less emotional impact of cancer, and greater perceived personal and treatment control over cancer (Gray et al., 2011; Jørgensen et al., 2009; Mickevičiene et al., 2013; Scharloo et al., 2005).

### **Discussion**

This systematic review and meta-analysis aimed to determine whether and how coping behaviours and illness outcomes in cancer are associated with illness representations in the Common Sense Model (CSM; Leventhal et al., 1980). The findings were generally consistent with our hypotheses and provided support for associations between the illness representation dimensions of the CSM, coping behaviours, and illness outcomes in cancer. The findings broadly replicated the patterns of associations between illness representations, coping, and illness outcomes in chronic illness (Hagger & Orbell, 2003), but add a specific cancer perspective, longitudinal data, and a narrative review of relevant studies. These findings have particular implications for the content of illness representation based interventions (Stanton, Luecken, MacKinnon, & Thompson, 2013).

Regarding coping behaviours, personal control perceptions appear to be the most promising areas to target to improve adaptive coping responses (cognitive reappraisal and problem-focused coping). In addition, emotional representations were associated with avoidance/denial coping behaviours. These findings are in line with Lazarus's general coping theory (Lazarus, 1993), as perceptions of control have been identified as preconditions for effective problem-focused coping, whereas emotional representations might foster emotion-focused coping responses to the cancer experience; as outlined in the parallel processing structure of the CSM. However, it is important to note that normative classifications of coping as adaptive or maladaptive are difficult, as factors such as cancer stage, time since

diagnosis, and outcome of the coping behaviour, can influence whether a coping strategy (such as avoidance/denial) would be considered adaptive or maladaptive (Salander & Windahl, 1999).

Regarding illness outcomes, higher levels of identity (perceived symptoms) and consequence perceptions were associated with higher levels of psychological distress, and lower levels of functioning and quality of life. Higher levels of control-related illness perceptions were associated with lower levels of distress and higher levels of functioning and quality of life. The findings for illness coherence had high heterogeneity, suggesting the relationships between coherence and illness outcomes may have been influenced by a moderator, such as treatment type. For example, an examination of the raw data suggested that those without an ostomy who had higher levels of illness coherence experienced better quality of life, physical and role functioning (better understanding is associated with better illness outcomes for people without an ostomy). In contrast, those with an ostomy and higher levels of illness coherence experienced poorer quality of life, physical and role functioning (better understanding is associated with worse illness outcomes for people with an ostomy) (Mols et al., 2014).

In general, the relationship between illness representations and coping behaviours were not as strong as those between illness representations and illness outcomes. This may be due to the fact that there were fewer studies examining coping behaviours than illness outcomes, so there was less power to detect effects (Cafri, Kromrey, & Brannick, 2010). Another explanation may be a potential overlap between illness representations and illness outcomes (e.g., consequences and quality of life or emotional representations and psychological distress). Further, as many studies were cross-sectional, emotional representations were likely to be highly correlated with measures of psychological distress. Finally, the level of specificity of the measures may influence the strength of these

relationships, in that illness outcomes (as more general evaluations of health status) may be more likely to correlate with illness representations than specific coping behaviours.

### **Implications and Future Research Directions**

For many people a cancer diagnosis is associated with acute and/or delayed emotional distress, clinical levels of depression and anxiety, poor role and physical functioning, and a poor quality of life (e.g., Bultz & Holland, 2006; Carlson et al., 2004; Croom et al., 2013; Edwards & Clarke, 2004). Some cancer survivors experience poor mental and physical health outcomes for up to ten years post diagnosis (Harrington et al., 2010). Further, coping with cancer is extremely complex (Parle, Jones, & Maguire, 1996), with maladaptive coping strategies such as avoidance or denial likely to lead to higher levels of worry, anxiety, and depression (Deimling et al., 2006). The current systematic review suggests that in order to foster coping behaviours and improve mental health outcomes it may be beneficial for interventions to target patients' maladaptive or unrealistic illness representations. It has been shown that mapping and challenging maladaptive illness representations, while at the same time forming alternative representations, can change both illness representations and role functioning, leading to improved psychosocial outcomes (Siemonsma et al., 2013). These findings are promising, and illness representations have been suggested as mediators of psychosocial intervention effects (Stanton et al., 2013). However, few intervention studies exist and none specifically target people with cancer or provide an explicit rationale for which illness representations to target.

The present review provides some suggestions for which illness representations might be best to target in interventions, though the cross-sectional nature of the majority of included studies precludes judgments regarding causality and suggestions must be considered with caution. Interventions that target perceptions of personal control may be useful to increase use of adaptive coping strategies such as cognitive reappraisal, and reduce maladaptive

coping strategies such as avoidance/denial. Further, interventions that aim to adapt timeline perceptions to be less cyclical and chronic, decrease perceptions of the severity of cancer, and decrease the perceived emotional impact of cancer, may reduce psychological distress, and improve role functioning, physical functioning, and quality of life.

In interventions targeting illness representations, it is important to acknowledge that some perceptions about poor illness outcomes may be realistic; for a person with terminal cancer, representations of a chronic timeline, severe consequences, and less personal control may be justified. In these cases interventions could better target illness representations such as emotional representations and coping. Future research should examine how stage of illness influences illness representations, and what type of interventions would be best for cancer patients at early versus advanced stages.

### **Strengths and Limitations**

Although the CSM has been used extensively to examine health and coping outcomes, the present systematic review is the first to assess illness representations with health and coping outcomes in people with cancer specifically, with the results helping to guide intervention development, particularly by deepening understanding of the nature of cognitive responses associated with the cancer experience. A further strength is the inclusion of a number of unpublished correlations obtained from authors, creating a comprehensive meta-analysis.

The present review has some limitations, including the potential for publication bias, missing correlational data, and the examination of cross-sectional and correlational data. To control for publication bias a random-effects model was used (Cafri et al., 2010). Although the focus on quantitative data may have potentially impacted on the results of the meta-analysis, the inclusion of the narrative review and synthesis aimed to avoid missing relevant or contrasting findings. In addition, an assessment of included studies suggested a low risk of

bias at the study level. However, as the majority of studies used cross-sectional study designs and correlational analyses, judgements regarding causality or predictive relationships between variables are precluded, limiting the conclusions to be drawn from this review. Further, zero-order correlations need to be interpreted with caution as it cannot be assumed that observed associations will remain stable if other illness representations are accounted for in multivariate analyses.

Another limitation is the potential for overlap between measures (i.e. illness representations and illness outcomes). For example, items assessing emotional representations and emotional distress may overlap, making these concepts difficult to entangle. However, the CSM assumes these to be distinct processes, with Moss-Morris et al. (2002) suggesting that emotional representations allow researchers to investigate both coping behaviours and illness outcomes. The authors of the IPQ-R claim to have ensured that the emotional representations concept was not simply a measure of general mood by ensuring discriminant validity with both positive and negative affect (Moss-Morris et al., 2002).

Consistent with recommendations by Weinman et al. (1996) and Moss-Morris et al. (2002) that users adapt the IPQ and IPQ-R to be illness specific, over fifty percent of studies included in the systematic review changed these to be ‘cancer specific’. Though each cancer specific adaptation could influence the reliability and validity of generic versus specific versions of the IPQ, this appears unlikely as the majority of changes involved simply replacing wording (e.g., Corter et al., 2013), or adjusting the identity and causes subscales to include items specifically related to cancer or a specific cancer type (e.g., Costanzo et al., 2011; Freeman-Gibb, 2012).

Several fail-safe Ns of zero were found in analyses with small numbers of studies included, suggesting a lack of statistical power (Card, 2012). However, as fail-safe N does not take into account heterogeneity, this may be an artefact of the heterogeneous population

in the meta-analysis (i.e. differing cancer types, cancer stages, and treatment types) (Card, 2012). There was high heterogeneity found across several relationships in the meta-analyses, and psychological distress and adaptability to cancer varies greatly with different types of cancer (Zabora & MacMurray, 2012) or cancer stages (Strada & Sourkes, 2010). However few studies reported this information, precluding moderator analyses on these variables. Similarly, treatment type or toxicity might also have impacted associations, with people at a higher risk for psychological distress when receiving treatment other than surgery or having little role in the treatment decision making process (Admiraal, Reyners, & Hoekstra-Weebers, 2013; Hack et al., 2010); but again there was insufficient data to allow moderator analyses, as underpowered moderator tests may result in failure to detect the true effect of an important moderator (Cafri et al., 2010).

### **Conclusions**

This systematic review has provided support for the validity of the illness representation construct in the CSM, and has summarised the associations between illness representations, coping behaviours and illness outcomes in people with cancer. The review found small to moderate relationships between illness representations and coping behaviours, and moderate to large relationships between illness representations and illness outcomes. These findings suggest that cognitive representations are key factors to understanding individual responses to cancer.

## **Chapter 3**

### **Study 2**

#### **Illness representations, coping, and illness outcomes in depression: A systematic review and meta-analysis\***

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\*Richardson, E. M., Schüz, N., Sanderson, K., Scott, J. L., Schüz, B. (2016). *Illness representations, coping, and illness outcomes in depression: A systematic review and meta-analysis*. Manuscript under review.



## Abstract

**Purpose:** The Common Sense Model is the leading psychological model of behavioural self-regulation in the face of illness, using subjective illness representations to explain how people cope with illness. However, this model has rarely been examined in the context of mental health. This review summarises associations between illness representations, health and coping outcomes in people with depression.

**Methods:** A systematic literature search identified 19 out of a potential 1,008 studies, with 10 providing sufficient data for random-effects meta-analysis, and nine included in a narrative review.

**Results:** Results found that more severe consequences were associated with more coping efforts, while higher identity, consequences, emotional representations, a more chronic timeline, and lower control were associated with more severe outcomes.

**Conclusions:** The illness representations identified seem to play an important role in behavioural self-regulation of depression. This suggests targeting these illness representations (in particular, identity, timeline, consequences, control, and emotional representations) in psychosocial interventions to improve coping and reduce psychological distress.

**Keywords:** depression; illness perceptions; common sense model of illness representations; systematic review; meta-analysis

Depression is a highly prevalent, disabling mental illness that is estimated to affect over 350 million people worldwide (Marcus et al., 2012). Depression has been associated with greater risk for physical disability (inability to perform activities due to impairment) (Brenes et al., 2008; Lenze et al., 2001), poor psychosocial functioning (Wells & Sherbourne, 1999), and poor quality of life (Brenes, 2007; Wells & Sherbourne, 1999). A key factor in both the etiology and treatment of depression are negative beliefs or schemas that lead to negative thoughts that occur when faced with adverse life events, leading to negative or depressed mood (A. T. Beck et al., 1979). These negative beliefs also influence how people with depression think about their illness, which in turn influences whether and how people cope with and manage depression, make treatment decisions, seek professional help, or adhere to anti-depressant medication (Lynch, Kendrick, Moore, Johnston, & Smith, 2006; Prins, Verhaak, Bensing, & van der Meer, 2008). These illness-related behaviours are perhaps best understood in light of a theory that explicitly addresses how people make decisions and cope with illness, which would suggest utilising theories from a Health Psychology rather than a Clinical Psychology background.

In order to understand the idiosyncratic patterns of beliefs that determine how people cope with their depression, the Common Sense Model of Self-Regulation of Health and Illness (CSM; Leventhal et al., 1980) should be considered. This model has been used widely to gain a systematic understanding of how people perceive chronic physical illnesses, and how this relates to coping attempts and illness outcomes. In order to establish whether the CSM might be a useful framework to inform Cognitive Behavioural Therapy (CBT; A. T. Beck et al., 1979), the currently most used and best-evidenced psychotherapeutic intervention for depression (Hofmann, Asnaani, Vonk, Sawyer, & Fang, 2012), our study aims to provide a systematic overview of the associations between the concepts from this theory, coping, and

illness outcomes in people with depression<sup>1</sup>.

In CBT-based treatments for depression (A. T. Beck et al., 1979; J. S. Beck, 2011), those thoughts and beliefs of a client (that are often negative or inaccurate) that contribute to the experience of depression are targeted for modification in an attempt to create lasting improved emotional and behavioural change. Here, negative automatic thoughts that lead to depressive symptoms are challenged through reality-testing and generating alternatives. To do this, the person with depression must first become familiar with their own negative automatic thoughts and the role they play in influencing their emotions and behaviours. This means that in order to treat depression successfully, both client and therapist need to find a common ground in defining and understanding depression (e.g., Tryon & Winograd, 2011), which underlines the importance of subjective illness concepts. This is where the Common Sense Model could make an important contribution. The CSM has been used as a framework with which to understand these cognitive processes in people with physical illnesses (Leventhal et al., 1980). According to the CSM, individual representations of the illness and associated emotional responses work in parallel to guide peoples' coping responses, which are later appraised in terms of their success or failure. Representations, coping, and appraisal are part of a multi-directional and self-regulative feedback loop (Diefenbach & Leventhal, 1996) (Figure 3.1).

The key factors that explain why and how individuals cope with their illness are subjective illness representations (or illness perceptions). These can be defined as individuals' common sense understanding of the illness (Leventhal et al., 1998; Leventhal et al., 1980). *Identity* ("What defines whether I have this illness?") refers to a person's associations with the label of the illness (e.g. "depression") and which symptoms someone

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<sup>1</sup> Anxiety was also included in the systematic search process; however only one study including anxiety was located and therefore it could not be examined in this review.

associated with this illness (e.g. fatigue). *Cause* refers to a person's beliefs about the causes of the illness (e.g. stress). *Timeline* refers to the perceived duration of the illness (e.g. acute or chronic). *Consequences* (both imagined and real) refer to perceived beliefs about the effect of the illness on an individual's life (e.g. loss of social life). *Curability* or *controllability* refers to people's perceptions about whether the illness can be controlled or cured by themselves or others (e.g. incurable but controllable with treatment) (Leventhal et al., 1998). Later revisions of the framework proposed that control beliefs have two distinct dimensions - *personal control* - the amount of control an individual perceives to have over the illness, and *treatment control* - the amount of control the individual perceives their treatment has over the illness. These revisions also included a distinct dimension for *cyclical timeline* perceptions, an *illness coherence* subscale to assess perceptions of an individual's understanding and comprehension of the illness, and a separate *emotional representations* subscale to assess the individual's emotional response to the illness (Moss-Morris et al., 2002).

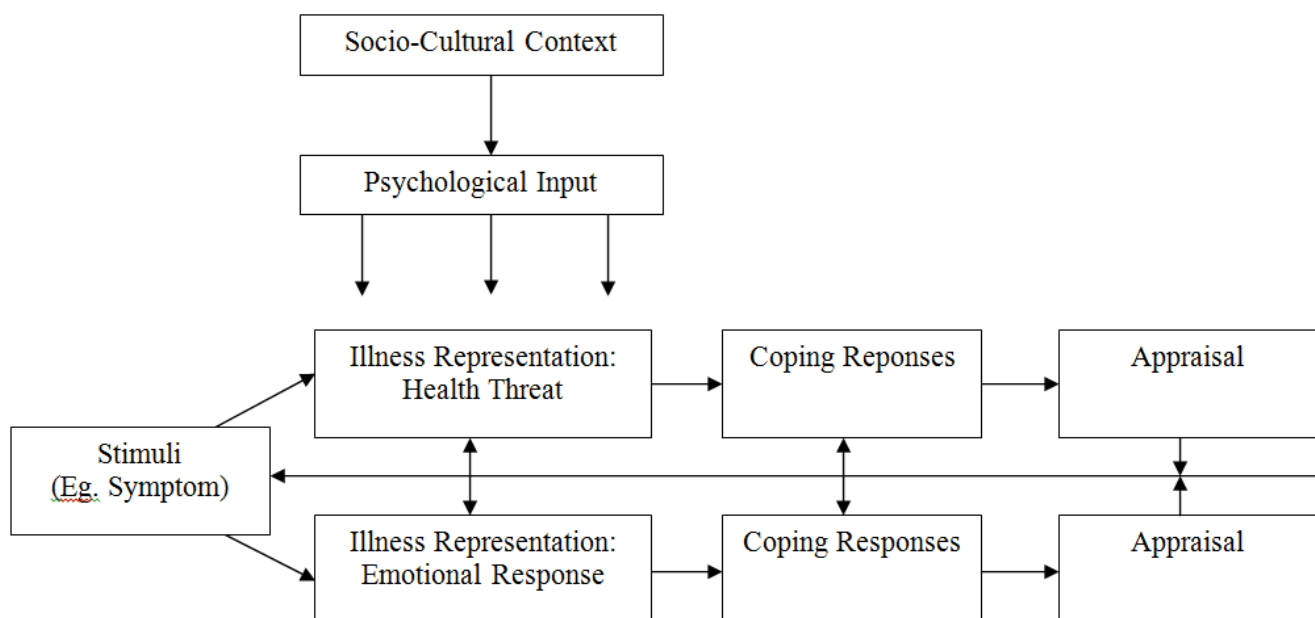


Figure 3.1. The common sense model of self-regulation of health and illness (Leventhal et al., 1980), adapted from Diefenbach and Leventhal (1996).

Illness representations play a key role in how people respond to and experience their illness. Systematic reviews on the CSM in physical illness (Hagger & Orbell, 2003) show that perceiving an illness as highly symptomatic with a chronic timeline and serious consequences is associated with maladaptive coping strategies such as denial, and negative illness outcomes such as lower role functioning; while perceptions of the illness as curable and controllable were associated with more adaptive coping strategies such as adherence to treatment, and positive illness outcomes such as psychological well-being. Focusing on depression and anxiety as illness outcomes, a recent review (Dempster et al., 2015) found very similar patterns, with perceptions of more serious consequences and greater emotional representations most strongly associated with higher levels of depression and anxiety. The associations identified in both reviews highlight that it is crucial to gain an understanding of individuals' subjective illness representations. However, neither of these previous systematic reviews took into account how these representations may be associated with coping behaviours and illness outcomes in people with depression.

Although the CSM was originally designed in the context of physical illness, it has also been successfully applied in mental illness (e.g., Akcakaya, 2012; Glattacker, Heyduck, & Meffert, 2013). This is likely due to the fact that mental illnesses such as depression require self-management and self-regulation, central components of the CSM. However, these relationships may be complicated by potential reciprocity between illness perceptions and depression, which may, for example, make it particularly difficult to disentangle emotional representations of depression from emotional symptoms of the illness (Alderson et al., 2012). Alderson et al. (2012) also note that depression illness perceptions might be more complex than those in physical illness, with depression identity and timeline beliefs highly idiosyncratic, and most participants perceiving complex multi-factor causes for their depression. Further, influenced by depressive schemas, some people with depression might

perceive no control over their depression at all.

A recent review on illness perceptions in mental illness in general by Baines and Wittkowski (2013) included a qualitative summary of four studies in people with depression. This summary revealed that identity, timeline, personal control, and consequences, were associated with depression severity; that identity, consequences, and control beliefs were associated with the use of particular coping behaviours; and that control beliefs, timeline, and causal beliefs were associated with medication adherence.

The CSM has led to an improved understanding of how people self-regulate their behaviours when faced with physical illness (Dempster et al., 2015; Hagger & Orbell, 2003). However, although two systematic reviews on CSM-based illness representations in mental illness exist (Alderson et al., 2012; Baines & Wittkowski, 2013), no previous review has quantitatively summarised and reviewed the evidence on the relationships between illness representations, coping behaviours, and illness outcomes in people with depression specifically. This might have particular implications for CBT-based treatments for depression: Although CBT has been shown to be effective at changing specific underlying beliefs found in depression (Hollon, Stewart, & Strunk, 2005), therapeutic interventions could be better targeted to illness-based cognitions. If we are able to identify a common pattern of beliefs that lead people with depression to engage in effective and adaptive behaviours, then specifically designed targeted CBT programs incorporating appropriate aspects of the CSM that aim to improve coping and reduce negative outcomes can be designed and implemented. The present review aims to synthesise the research that examines how such beliefs are related to coping and illness outcomes in order to provide appropriate direction for the creation of such tailored interventions.

## **Method**

### **Literature Search, Inclusion Criteria, and Study Selection**

This systematic review followed PRISMA guidelines (Moher et al., 2009, Appendix 3.1). The following databases were searched: *Scopus*, *Web of Science*, *PubMed*, *PsycINFO*, and *Google Scholar*. The keywords were: (anxiety OR "anxiety disorder\*" OR depress\* OR "depress\* disorder\*") AND ("illness perception\*" OR "illness representation\*" OR "common sense" OR Leventhal\* OR IPQ\*). See Appendix 3.2 for the full search strategy for each database. Manual searches of reference lists of included articles were conducted to identify additional studies for review, with attempts to locate missing data sets undertaken by contacting relevant authors.

Inclusion criteria for studies in this review were: (a) used the Illness Perception Questionnaire (IPQ; Weinman et al., 1996), the Revised IPQ (IPQ-R; Moss-Morris et al., 2002), or the Brief IPQ (B-IPQ Broadbent et al., 2006), (b) measured coping behaviours or illness outcomes, (c) adult participants (over 18 years) with a diagnosis of depression or anxiety, (d) was written in English or German.

Following database screening, 2098 articles were identified, with 1008 articles remaining following duplicate removal. Of these, 965 studies were removed for not meeting inclusion criteria. Inter-rater agreement between two authors during abstract screening was 68.63% (Cohen's Kappa = .69). Full texts were retrieved of the remaining 43 articles, with a further 26 excluded. Two additional studies were found and included following a manual search of the reference lists, which left 19 studies for coding (manual and coding sheet in Appendix 3.3 and 3.4). Ten studies provided appropriate and relevant statistical data and could be included in the meta-analysis (Akçakaya, 2012; Baines, Wittkowski, & Wieck, 2013; C. Brown et al., 2001; Cabassa, Lagomasino, Dwight-Johnson, Hansen, & Xie, 2008; Fortune, Barrowclough, & Lobban, 2004; Glattacker et al., 2013; Horn, Kneisler, Schuster, & Traue, 2010; Houle et al., 2013; Lu et al., 2014; Vollmann et al., 2010), with the remaining nine studies subject to a narrative review (C. Brown et al., 2007; Elwy et al., 2016; Elwy et

al., 2011; Hunot, Horne, Leese, & Churchill, 2007; Kelly, Sereika, Battista, & Brown, 2007; Mc Sharry et al., 2013; O'Mahen, Flynn, Chermack, & Marcus, 2009; Patel, Wittkowski, Fox, & Wieck, 2013; E. C. Ward, Mengesha, & Issa, 2014). A flow chart of the study selection process is displayed in Figure 3.2. See Table 3.1 for a summary of key characteristics of the studies.

### **Coding of Coping Behaviours and Illness Outcomes**

The coping behaviours included in the articles reviewed were categorised into logical subsets using categories adapted from Hagger and Orbell (2003), with seven categories identified: expressing emotion, avoidance/denial, problem-focused coping (generic), treatment decision making, medication adherence, seeking social support, and other (specified) coping behaviour. Due to small cell sizes (most of these coping categories were only populated by one study), these categories were collapsed into one 'coping' scale which measured the extent to which participants used or did not use the above specified coping behaviours.

Illness outcomes were also classified using adapted and extended categories identified by Hagger and Orbell (2003), resulting in nine categories: affect (positive), anxiety, depression (severity), psychological distress, psychological well-being, vitality, role functioning, physical functioning, other illness outcome (general health). Similar to the classification of coping behaviours, small cell sizes prevented an analysis of distinct categories, and analogous to Hagger and Orbell (2003), affect, anxiety, depression, psychological distress, and psychological well-being were collapsed into one 'psychological distress' dimension. Although it may seem circular to examine psychological distress when our population of interest is people with depression, some illness representations are associated with less psychological distress (e.g., control perceptions), suggesting that this relationship is of practical importance.



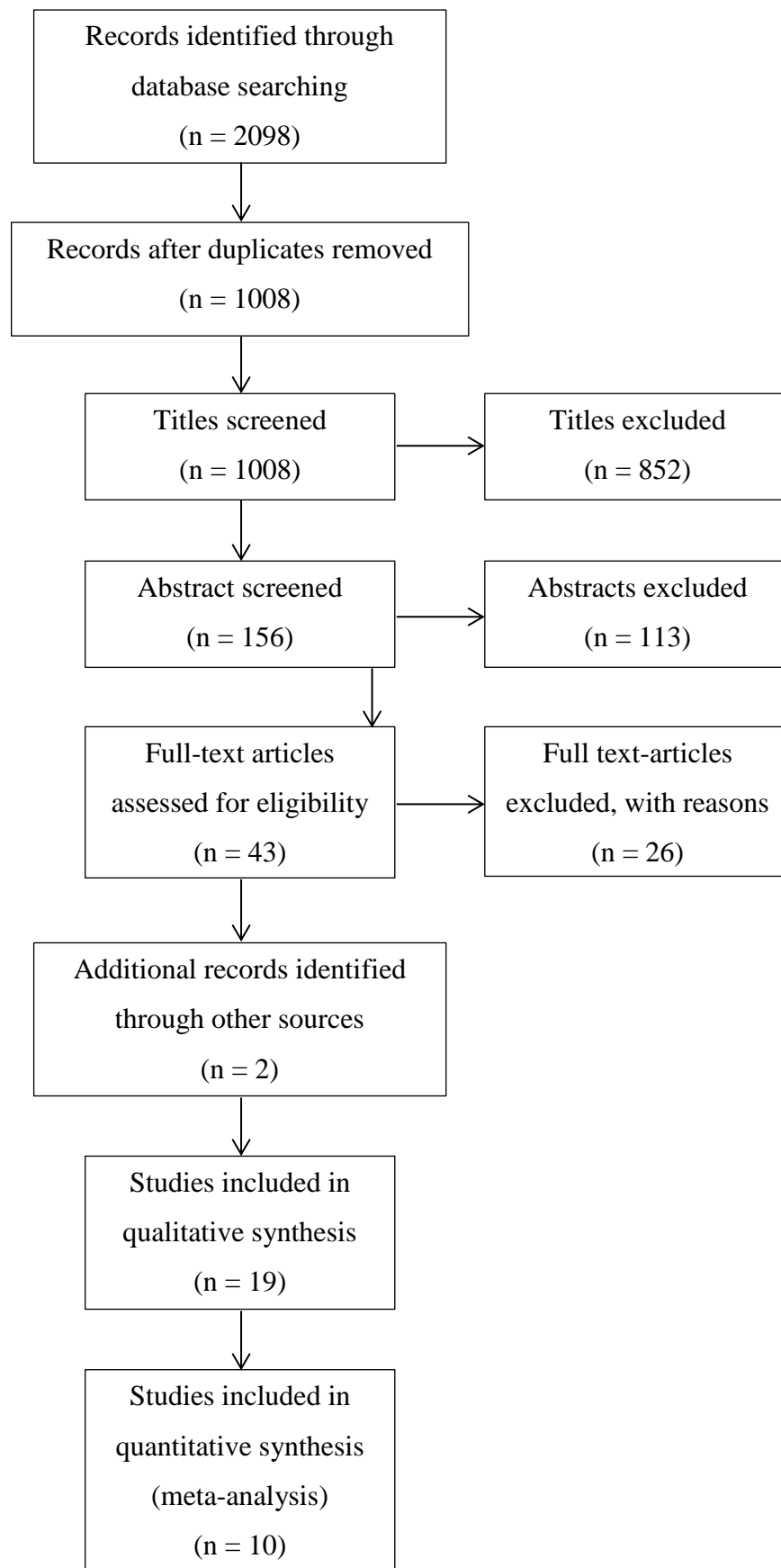


Figure 3.2. Flow chart of the study selection process.

Table 3.1  
Data Extraction and Study Characteristics

Authors (Date)	Depression or Anxiety	Sample Size (Completed all Time Points)	Sex (T1)	Age (T1)	Study Design	IPQ Type	Coping Behaviour	Illness Outcome	Relevant Results
Akcakaya (2012)	Depression	112	60% Male	$M = 59$ , $SD = 10.3$ , Range = 30 - 81	Longitudinal	IPQ-R: Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Depression (Severity), Anxiety	Consequences, timeline (acute/chronic), and emotional representations were significantly related to depression severity, while only emotional representations were significantly related to anxiety.
Baines, Wittkowski, & Wieck (2013)	Depression (Postpartum)	43	100% Female	$M = 29.36$ , $SD = 5.79$ , Range = 18 - 40	Longitudinal	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Depression (Symptom Severity)	More perceived symptoms (higher identity scores), a more chronic timeline, less perceived personal control, and higher rates of emotional distress, were significantly related to depression symptom severity.
Brown, Battista, Sereika, Bruehlman, Dunbar-Jacob, & Thase (2007)	Depression	191	70.68% Male	$M = 45.1$ , $SD = 15.9$	Cross-sectional	IPQ	Multiple - e.g., Expressing Emotion, Cognitive Reappraisal, Avoidance/Denial, Other	Multiple - e.g., Depression, Physical Functioning	Illness representations associated with psychosocial functioning included perceived control, perceived duration, and perceived cause of depressive symptoms. Several coping behaviours (e.g., expressing emotion, cognitive reappraisal, avoidance/denial) mediated or moderated the relationship between illness representations and psychosocial functioning.
Brown, Dunbar-Jacob, Palenchar, Kelleher, Bruehlman, Sereika, & Thase (2001)	Depression	41	66% Female	$M = 43$ , $SD = 15.7$	Cross-sectional	IPQ: Identity, Cause, Timeline, Consequences, Controllability,	Expressing Emotion, Avoidance/Denial, Problem-Focused Coping Generic (x2), Other Coping Behaviour (x2) (Self-Blame, Religion), Medication Adherence		Perceived negative consequences for depression were associated with more active coping, religious coping, and self-blame, while perception of depressive symptoms as more chronic was associated with less planning. Perception of more depressive symptoms (increased identity) was associated with more self-blame, avoidance, and venting.
Cabassa, Lagomasino, Dwight-Johnson, Hansen, & Xie (2008)	Depression	339	83.78% Female	$M = 49.73$ , $SD = 12.53$	Cross-sectional	IPQ-R: Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control		Depression (Symptom Severity)	Perceptions of a more chronic timeline was significantly related to greater depression symptom severity, while perceptions of a less cyclical timeline were related to greater depression symptom severity (though not significantly).
Elwy, Glickman, Bokhour, Dell, Mueller, Zhao, Osei-Bonsu, Rodrigues, Coldwell, Ngo, Schlosser, Vielhauer, Pirraglia, & Eisen (2013)	Depression	271	93.3% Male	Range = 20 - 71+	Longitudinal	IPQ-R: Identity, Cause, Timeline - Acute Timeline - Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, External Control Illness Coherence, Emotional Representations	Treatment Decision Making		Veterans perceptions of their symptoms, cause, timeline (cyclical), and personal controllability, predicted receiving guideline-concordant treatment for depression.

Elwy, Yeh, Worcester, & Eisen (2011)	Depression	30	53.33% Male	$M = 44$ , Range = 20 - 61	Qualitative	IPQ-R	Treatment Decision Making	Those who sought treatment for depression had a better understanding of depression (illness coherence), perceived treatment would control their depression, and that there would be negative consequences if they did nothing. In contrast, those who did not seek treatment perceived that treatment would not control their depression, that the depression would be short-term, and that depression did not affect their everyday life.
Fortune, Barrowclough, & Lobban (2004)	Depression	101	100% Female	$M = 33$ , $SD = 5.5$	Cross-sectional	IPQ: Identity, Cause, Timeline, Consequences, Control/Cure	Depression (Severity)	Depression severity was significantly related to perception of more symptoms (identity), a more chronic timeline, more severe consequences, and less perceived personal control.
Glattacker, Heyduck, & Meffert (2013)	Depression	80	74% Female	$M = 48.5$ , $SD = 9.5$	Longitudinal	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Physical Functioning (x2) (Pain), Role Functioning (x3) (Physical, Emotional, Social), Other Illness Outcome (Self-Rated General Health), Vitality, Psychological Well-Being, Depression (Symptom Severity)	Illness perceptions were related to functioning. The strongest predictors of functioning were generally identity, consequences, and timeline (acute/chronic).
Horn, Kneisler, Schuster, & Traue (2010)	Depression	59	69.49% Female	$M = 46$ , $SD = 8.7$ , Range = 25 - 62	Longitudinal	IPQ-R: Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Depression (Symptom Severity), Affect (Positive)	Perceptions of a more cyclical timeline, more severe consequences, and stronger emotional representations were associated with increased depression symptom severity, while perceptions of a more chronic timeline, more severe consequences, stronger emotional representations, less personal control, and less illness coherence were associated with decreased positive affect.
Houle, Villaggi, Beaulieu, Lespérance, Rondeau, & Lambert (2013)	Depression	88	53.4% Male	$M = 42$ , $SD = 12.2$	Cross-sectional	IPQ-R: Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Treatment Decision Making (x3) (Antidepressant Acceptability, Psychotherapy Acceptability, Psychotherapy Preference)	A perceived chronic timeline of depression was associated with preference for psychotherapy treatment, higher levels of treatment control was associated with higher levels of antidepressant acceptability, and a perception of more severe consequences of depression was associated with higher levels of psychotherapy acceptability.

Hunot, Horne, Leese, & Churchill (2007)	Depression and Anxiety	147	75% Female	$M = 40.1$ , $SD = 12.6$	Longitudinal	IPQ-R	Medication Adherence		Illness perceptions were not associated with antidepressant adherence. Greater emotional reactions to depression were associated with maladaptive coping for both men and women, while greater perceived control over depression was associated with more adaptive coping strategies for women.
Kelly, Sereika, Battista, & Brown (2007)	Depression	189	70.4% Female	$M = 45.19$ , $SD = 15.91$ , Range = 18 - 87	Cross-sectional	IPQ: Identity, Cause, Timeline, Consequences, Control/Cure, Emotional Reactions	Multiple - e.g., Expressing Emotion, Cognitive Reappraisal, Avoidance/Denial, Treatment Decision Making, Other		Perceived chronic timeline, more severe consequences, less perceived personal control, and stronger emotional representations were associated with severity of depression, anxiety, stress, and negative emotions (psychological distress). Adaptive rumination was most strongly related to perceptions of a less chronic timeline, while maladaptive rumination was most strongly related to a perception of more severe consequences.
Lu, Tang, Shan Liow, Wei Ni Ng, Su Hui Ho, & Chun Mun Ho (2014)	Depression	110	54% Female	$M = 41.7$ , $SD = 12.3$ , Range = 19 - 67	Cross-sectional	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Cognitive Reappraisal (Adaptive Rumination), Other Coping Behaviour (Maladaptive Rumination)	Depression, Anxiety, Psychological Distress (x2) (Stress, Negative Emotions)	Diabetes and depression representations varied for those who saw interactions between conditions (e.g. in terms of causation), and those who saw their conditions as unrelated. Problems with medication adherence were frequently described, often with respect to the difficulty of living with multimorbid conditions.
Mc Sharry, Bishop, Moss-Morris, & Kendrick (2013)	Depression	17	52.9% Female	Range = 31 - 78	Qualitative	CSM Generally	No specific DV	No specific DV	Beliefs in a more chronic timeline for depression symptoms significantly predicted treatment use.
O'Mahen, Flynn, Chermack, & Marcus (2009)	Depression (Perinatal)	82	100% Female	$M = 30.02$ , $SD = 4.9$ , Range = 19 - 39	Longitudinal	IPQ: Cause, Timeline, Consequences, Control/Cure	Other Coping Behaviour (Treatment Use)		Although participants identified with PND, the CSM dimensions did not map onto the key themes identified - which were more related to self-worth.
Patel, Wittkowski, Fox, & Wieck (2013)	Depression (Postnatal)	11	100% Female	$M = 29.4$ , Range = 22 - 35	Qualitative	CSM Generally	No specific DV	No specific DV	Activation-oriented support was regarded as more helpful when people perceived depression as less chronic, as more controllable by treatment, and as caused by immunity malfunction.
Vollmann, Scharloo, Salewski, Dienst, Schonauer, & Renner (2010)	Depression	41	56.10% Female	$M = 49.56$ , $SD = 10.40$ , Range = 17 - 67	Cross-sectional	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Social Support (x5)		Women generally believed that depression was a normal reaction to life circumstances and that culturally sanctioned coping behaviours (e.g. religion and resilience) were appropriate. These factors may provide a barrier for seeking professional mental health care.
Ward, Mengesha, & Issa (2014)	Depression	13	100% Female	$M = 71$ , Range = 60 - 78	Qualitative	CSM Generally	No specific DV	No specific DV	

## Data Extraction and Meta-Analytic Strategy

From all articles included in the systematic review, authors and date of publication, depression type, sample characteristics (sex and age), study design, IPQ version and subscales, coping behaviours, illness outcomes, and a summary of relevant results were extracted (Table 3.1).

Zero-order correlations were the most frequently reported effect size in the included studies. Thus the average correlation coefficient weighted by sample size and calculated using Fischer's  $Z$  transformations ( $r_z$ ). Where necessary, correlations were reversed to maintain consistency across studies (i.e., correlations with psychological well-being were reversed). If more than one measure was used by a single study to assess an outcome within the same category (e.g., emotional social support and informational social support), the average weighted correlation coefficient was calculated and used in order to avoid bias. Further, to minimise heterogeneity due to design, only the baseline (Time 1) result was used for longitudinal studies that measured an outcome at more than one time point. Eight authors were contacted to provide correlations not reported in the articles, with responses from four authors received, and three authors able to provide the relevant data required for meta-analysis. The remaining articles were included in a narrative review.

The meta-analyses were conducted in R (R Core Team, 2014) using the 'metafor' package (Viechtbauer, 2010). A random-effects meta-analysis was conducted, which allows for the assumption that the true effect size (the effect size in the underlying population of studies) may vary from study to study as a result of heterogeneity (Borenstein et al., 2010). The studies were likely to be heterogeneous in the present meta-analysis because of differing design, depression types, treatment types, and other sampling characteristics.

To assess heterogeneity between studies,  $Q$  and  $I^2$  statistics were calculated. The  $Q$  statistic assesses the ratio of the variation in the observed effects to the within-study error,

suggesting heterogeneity when statistically significant (Huedo-Medina, Sanchez-Meca, Marin-Martinez, & Botella, 2006). The  $I^2$  statistic indicates the percentage of variance across studies that can be attributed to heterogeneity rather than chance, with increasing values representing increasing heterogeneity. While the  $I^2$  statistic gives an indication of the extent of true heterogeneity, the  $Q$  statistic provides only an indication of statistical significance. An  $I^2$  value of 25% is considered low, 50% considered moderate, and 75% considered high (Higgins, Thompson, Deeks, & Altman, 2003).

## **Results**

### **Study Characteristics**

Sample sizes ranged between 11 and 339 ( $M = 103$ ). One study included participants with both anxiety and depression (Hunot et al., 2007), and three studies examined perinatal/postnatal/postpartum depression specifically (Baines et al., 2013; O'Mahen et al., 2009; Patel et al., 2013). All studies except one (90%) adapted the IPQ to be 'depression specific', rather than using a generic measure of illness representations. This involved minor changes in wording and the inclusion of depression specific symptoms and causes, and accordingly resulted in some heterogeneity with regards to the assessment of depression. See Table 3.1 for more key study characteristics.

### **Risk of Bias Assessment**

Risk of bias was evaluated using four criteria relevant to the research aims assessed: (i) whether each version of the IPQ was administered as recommended; (ii) which IPQ dimensions were reported and assessed; (iii) study design; (iv) whether confounding variables were adjusted for. With respect to administration of the IPQ, IPQ-R, or B-IPQ, 36.64% of studies adhered to guidelines by developers (lower risk of bias), 31.58% partially adhered to guidelines by developers (medium risk of bias), and 31.58% used the CSM as a theoretical basis for qualitative interviews or did not adhere to developers' guidelines (higher risk of

bias). The majority of studies (68.42%) assessed and reported all measured illness representation dimensions (lower risk of bias), with 5.26% assessing but not reporting all measured illness representations dimensions (medium risk of bias), and 26.32% not assessing nor reporting all measured illness representation dimensions (higher risk of bias). With regard to study design, 36.84% of studies were longitudinal (lower risk of bias), 42.11% of studies were cross-sectional (medium risk of bias), and 21.05% of studies were qualitative (high risk of bias). Only one study (C. Brown et al., 2001) adjusted for potential confounds (low risk of bias). See Appendices 3.5 and 3.6 for summary tables and a graph on risk of bias.

### **Relationship of Illness Representations to Coping and Psychological Distress:**

#### **Quantitative Analysis**

Table 3.2 shows that only the relationships between acute/chronic timeline and coping and acute/chronic timeline and psychological distress were subject to high heterogeneity ( $I^2 = 73.02$  and  $I^2 = 71.02$  respectively). The remaining  $I^2$  values indicate moderate to low heterogeneity.

The results from the meta-analyses between coping and illness representations represented small to moderate effects (following Cohen, 1992), while the results between psychological distress and illness representations represented small to large effects (Table 3.2, Forest plots in Appendix 3.7). The strongest correlate of coping was consequences, with more depression-related consequences indicating more use of coping behaviours (both adaptive and maladaptive),  $r_z = .205$ , 95% CI [.051, .360]. The next strongest correlates included cause ( $r_z = .194$ , 95% CI [-.245, .632]) and treatment control ( $r_z = .162$ , 95% CI [-.014, .339]).

Overall, there were stronger and more significant relationships between illness representations and psychological distress than between illness representations and coping. The strongest correlate of psychological distress was emotional representations, with higher

levels of emotional representations (stronger emotional responses to depression) indicating more psychological distress,  $r_z = .481$ , 95% CI [.378, .583]. Other correlates included identity  $r_z = .442$ , 95% CI [.289, .595], consequences  $r_z = .435$ , 95% CI [.296, .573], acute/chronic timeline  $r_z = .330$ , 95% CI [.193, .466], and personal control  $r_z = -.253$ , 95% CI [-.384, -.122]. Treatment control  $r_z = -.151$ , 95% CI [-.301, -.002] and illness coherence  $r_z = -.105$ , 95% CI [-.202, -.007] were also statistically significantly related to psychological distress, but had smaller effect sizes. It is worth noting here that similar results and effect sizes were found for both cross-sectional and longitudinal data when analysed separately.

Across all relationships funnel plots (Appendix 3.8) were generally symmetrical, suggesting that publication bias was unlikely (Light & Pillemer, 1984). The number of studies that fell outside the funnel varied between none and two, with those points falling outside the plot likely to represent heterogeneity in the data. Fail-safe N ranged from zero to 198 across the relationships between illness representations and coping and illness representations and psychological distress (see Table 3.2). This suggests that we can only be confident that some of the relationships identified would not be altered by finding a large number of missing or unpublished contradictory data (Rosenthal, 1979).

### **Relationship of Illness Representations to Coping and Psychological Distress: Narrative Review**

Nine of the 19 studies did not report relevant data, or data could not be obtained from authors on request. Using thematic analysis, we conducted a narrative review of these studies and identified four common themes. These themes broadly replicate the findings of the meta-analysis.

One theme related to perceptions of specific causes of depression that influenced both coping behaviours and illness outcomes. Elwy et al. (2016) found that veterans who perceived the cause of their symptoms to be family problems were less likely to receive



Table 3.2

*Meta-Analyses of the Relationships between Illness Representations and Coping, and Illness Representations and Psychological Distress*

	Coping							Psychological Distress						
	<i>k</i>	<i>N</i>	<i>r<sub>z</sub></i>	(95% CI)	<i>N<sub>fs</sub></i>	<i>Q</i>	<i>I<sup>2</sup></i>	<i>k</i>	<i>N</i>	<i>r<sub>z</sub></i>	(95% CI)	<i>N<sub>fs</sub></i>	<i>Q</i>	<i>I<sup>2</sup></i>
Identity								4	342	.442***	(.289, .595)	89	5.68	48.16
Cause	2	48	.194	(-.245, .632)	0	1.25	19.92							
Timeline (Acute/Chronic)	3	169	-.084	(-.397, .228)	0	6.88*	73.02	7	858	.330***	(.193, .466)	183	23.88***	71.02
Timeline (Cyclical)								6	759	.069	(-.003, .141)	5	3.14	<.01
Consequences	3	170	.205**	(.051, .360)	5	2.33	<.01	6	520	.435***	(.296, .573)	198	12.09*	58.37
Personal Control	2	129	.048	(-.129, .225)	0	<.01	<.01	5	419	-.253***	(-.384, -.122)	42	6.69	41.82
Treatment Control	2	129	.162	(-.014, .339)	1	.39	<.01	5	418	-.151*	(-.301, -.002)	12	9.11	55.12
Illness Coherence	2	129	.089	(-.087, .266)	0	.03	<.01	5	419	-.105*	(-.202, -.007)	4	1.58	<.01
Emotional Representations	2	129	.067	(-.109, .244)	0	.97	<.01	5	420	.481***	(.378, .583)	163	3.61	8.23

*Note.* *k* = number of studies, *N* = total sample size across included studies, *r<sub>z</sub>* = effect size, (95%CI) = 95% confidence intervals around the effect size, *N<sub>fs</sub>* = Rosenthal's fail-safe N (measure of publication bias), *Q* = measure of heterogeneity (suggests heterogeneity when statistically significant), *I<sup>2</sup>* = measure of heterogeneity (25% = low, 50% = moderate, 75% = high), \**p* < .05, \*\**p* < .01, \*\*\**p* < .001

guideline-concordant treatment following a positive screen for depression. E. C. Ward et al. (2014) found that older African American women generally perceived that their depression was a normal reaction to life circumstances and that culturally accepted behaviours such as religion and resilience were appropriate strategies for coping with such depression. These studies suggest that perceiving external and stable causes for depression is associated with less help-seeking. C. Brown et al. (2007) suggests mechanisms for the cause-coping relationship by showing that the coping behaviours venting and self-blame mediated the relationship between the perceived cause stress and interpersonal problems (outcome).

A second theme revolved around the effects of timeline perceptions and treatment seeking, but with more heterogeneous results. A more chronic timeline predicted treatment use (antidepressant or psychotherapy/counselling) (O'Mahen et al., 2009), while those who did not seek treatment for depression perceived a more acute or cyclical timeline (Elwy et al., 2016; Elwy et al., 2011). In contrast, E. C. Ward et al. (2014) highlight that a perceived chronic timeline of depression may be a barrier to seeking appropriate professional mental health care. Further, C. Brown et al. (2007) found that two coping behaviours (behavioural disengagement and self-blame) partially mediated the relationship between perceived timeline of depression and psychosocial functioning.

The third theme was related to the role of consequences for coping, which also revealed some diverse patterns and relationships. The perception of less severe consequences of depression in one's day-to-day life was associated with reduced treatment seeking (Elwy et al., 2011), but at the same time, perceiving more severe consequences of depression was associated with less problem-solving oriented coping strategies and more maladaptive coping strategies such as behavioural disengagement or rumination (Kelly et al., 2007).

A fourth theme emerged around the relationship of control perceptions and coping behaviours. Higher levels of control perceptions were associated with less likelihood of

receiving guideline concordant treatment for Veterans (Elwy et al., 2016). However, contrary to this, higher treatment control perceptions were associated with more treatment seeking (Elwy et al., 2011). In addition, higher treatment and personal control perceptions were associated with the use of more adaptive coping strategies, such as problem solving, positive reframing, and active coping, for women (Kelly et al., 2007). While on the other hand, low control perceptions predicted behavioural disengagement which in turn predicted lower psychosocial functioning (C. Brown et al., 2007).

A further three studies could not be easily or clearly synthesised using thematic analysis. Hunot et al. (2007) found no significant relationship between continued antidepressant use and illness representations, and non-continued antidepressant use and illness representations. Mc Sharry et al. (2013) examined multimorbid illness representations and self-management in people with depression and diabetes. They found that diabetes and depression representations varied for those who perceived interactions between each condition (e.g., in terms of causation), and those who saw their illnesses as unrelated. These multimorbid representations were described as impacting on participants' self-management. For example, due to the difficulty of living with multimorbid conditions, problems with medication adherence were commonly described. Finally, Patel et al. (2013) examined illness representations in mothers with postnatal depression using semi-structured interviews and concluded that the themes identified from these interviews did not clearly map onto the key illness representation dimensions of the CSM. Instead, this study revealed more complex conceptualisations of postnatal depression that seemed to be attached to mothers' sense of self and self-worth.

In summary, this narrative review broadly replicates the findings from the meta-analyses, with the majority of studies finding and reporting some association between illness representations and coping behaviours or illness representations and illness outcomes.

## **Discussion**

The aim of this systematic review and meta-analysis was to determine whether and how illness representations are associated with coping behaviours and illness outcomes for people with depression. The CSM has been used extensively to examine health and coping outcomes in physical illness, however the present systematic review and meta-analysis was the first to assess the associations of illness representations specifically with health and coping outcomes in people with depression. This review provides new insights into the utility of the CSM for mental health, and can be used as the basis for interventions aimed at improving the health and coping outcomes of those with depression.

### **Illness Representations and Coping Behaviours**

The strongest relationship with regard to coping identified in the meta-analysis was between consequences and the use of coping behaviours, with perceptions of more severe consequences associated with the use of more coping behaviours. The narrative review also found more severe consequences to be associated with the use of more coping strategies (including behavioural disengagement and rumination), though more severe consequences were also found to be associated with less treatment seeking. When combined, this suggests that the more severe people perceive the consequences of depression to be, the more likely they are to use various strategies to cope with it, but at the same time seem less likely to seek treatment. To understand this seemingly paradoxical relationship with both more maladaptive and less adaptive coping strategies, control beliefs might be of importance. More personal and treatment related control were associated with the use of not only more coping strategies, but specifically with the use of more adaptive coping strategies (including positive reframing, problem solving, active coping, and treatment seeking). This means that the more control a person feels over their depression, and the more control a person feels that their treatment has over their depression, the more likely that person is to use an adaptive coping strategy. This

finding is in line with research examining physical health conditions and recommendations for best practice in CBT. Finally, the narrative review also found that a more chronic timeline was associated with less treatment seeking. Taken together, these findings suggest that in order to increase the use of coping strategies it may be beneficial to target beliefs around consequences, both personal and treatment control, and chronicity of timeline. For example, personal control beliefs can be targeted in traditional CBT interventions that encourage patients to take more control over depressive thoughts, symptoms, and feelings (J. S. Beck, 2011), but at the same time exploring causal and timeline beliefs might enrich CBT practice and provide target points for cognitive restructuring. In addition, interventions that explicitly target beliefs about depression and its treatment could remove barriers to treatment adherence (Elwy et al., 2011).

### **Illness Representations and Illness Outcomes**

Findings from our meta-analysis matched previous reviews (Baines & Wittkowski, 2013; Dempster et al., 2015; Hagger & Orbell, 2003), with higher identity (perceived symptoms), perceptions of a more chronic timeline, perceptions of more severe consequences, and stronger emotional representations, associated with more psychological distress. In contrast, higher perceived personal and treatment control, as well as stronger illness coherence, were found to be associated with lower levels of psychological distress. The narrative review generally revealed similar patterns of relationships between illness representations and illness outcomes. These findings suggest that identity, timeline, and control perceptions are the key illness representations to target in therapeutic interventions. For example, psychoeducational strategies could focus on increasing understanding and perceived control over depression, correcting beliefs regarding treatment control and the expected timeline of depressive episodes, reducing consequences and perceptions of severe consequences of depression, and improving emotional responses to depression.

## **Implications**

The current systematic review suggests that in order to both improve and increase the use of coping strategies, and improve mental illness outcomes such as psychological distress, it would be beneficial to target unrealistic or maladaptive illness representations in evidence-based psychosocial interventions. For people with some chronic physical illnesses it has been shown that challenging maladaptive illness representations and forming alternate representations can both change illness representations and lead to improved psychosocial outcomes (Siemonsma et al., 2013). However, although such findings are promising, only few intervention studies exist (with none specifically targeting depression). Further, very few of these intervention based studies provide an explicit rationale for which illness representations are best to target. The present review provides some suggestions for which illness representations would be best to target in intervention trials – in particular perceived control. Further, interventions aimed at adapting timeline perceptions to be less chronic, decreasing perceptions of severe consequences of depression, and reducing the perceived emotional impacts of depression, may lead to less psychological distress.

## **Limitations**

This review is limited by a lack of quantitative research examining the relationship between illness representations and specific coping behaviours, meaning that instead of assessing which representations were associated with the use of adaptive versus maladaptive coping strategies, we were only able to examine which illness representations were associated with the use of coping strategies in general. This lack of data also led results to suggest that the relationships between illness representations and coping behaviours were not as strong as those between illness representations and illness outcomes. However, the limited quantitative results, combined with the findings from the qualitative review, do provide some interesting insights into the relationships between illness representations and coping behaviours in

people with depression.

It can be argued that a substantial overlap between depression, the illness outcomes measured (psychological distress), and illness representations (particularly emotional representations) precludes interpreting relationships between these factors. It seems obvious that if a person is depressed, this will influence their illness perceptions and the extent to which they experience psychological distress. However, according to Cognitive Theory (Clark & Watson, 1991), people have relatively stable core beliefs that can influence how people interpret and respond to specific information, and these core beliefs also impact individuals' interpretation of illness. Therefore, specific illness representations may not only be influenced by how an individual perceives the illness, but also by their more generalised core beliefs.

There is also the potential for overlapping items assessing depression, illness outcomes (psychological distress), and illness representations. For example, at times items assessing emotional representations and items assessing psychological distress may overlap, making these concepts difficult to entangle. However, the development process of the IPQ-R suggests discriminant validity between the emotional representations construct and positive and negative affect (Moss-Morris et al., 2002). In future, studies should take care to use items and measures that assess each individual construct as uniquely as possible to ensure appropriate discriminant validity is achieved.

An assessment of included studies suggests some risk of bias at the study level, particularly when examining administration and modification of the IPQ, IPQ-R, and B-IPQ. These adaptations have the potential to differ substantially from the original questionnaires, meaning that the reliability and validity of the IPQ/IPQ-R may be affected. However, as the majority of studies included in the present review have adjusted the IPQ or IPQ-R by replacing generic wording to be more specific (e.g., illness for depression), or by adjusting

the identity and causes subscales to assess symptoms and causes that relate specifically to depression, this appears unlikely.

## **Conclusion**

This systematic review provides support for the validity of the CSM's illness representation dimensions for predicting illness outcomes (specifically psychological distress) in people with depression. Our findings suggest that such representations including perceived control, timeline, consequences, identity, and emotional representations are key to understanding how people respond to depression. These relationships can inform CBT-based interventions that target inaccurate or maladaptive illness representations. However, the low number and varying quality of the studies reviewed suggests that more high-quality research is needed before we can confirm which dimensions underlie the subjective illness understandings of people with depression.



## Chapter 4

### Study 3

#### **‘It was all intertwined’: Illness representations and self-management in people with cancer and anxiety/depression\***

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\*Richardson, E. M., Scott, J. L., Schüz, N. Sanderson, K., & Schüz, B. (2016). *‘It was all intertwined’: Illness representations and self-management in people with cancer and anxiety/depression*. Manuscript under review.

## Abstract

**Objective:** Cancer and anxiety/depression frequently co-occur, leading to poorer outcomes for these illnesses. However, the majority of existing research investigates how participants view single illnesses alone. This study aimed to explore the content of individuals' multimorbid representations and how these relate to their coping behaviours and self-management strategies for cancer and anxiety/depression.

**Design:** A semi-structured qualitative research design with theoretical thematic analysis.

**Main Outcome Measures:** Multimorbid illness representations, coping behaviours, and self-management strategies.

**Results:** In interviews with 21 participants multimorbid representations varied, with three participants viewing cancer and anxiety/depression as unrelated, five participants uncertain about the relationship between cancer and anxiety/depression, and the majority of participants (13) perceiving cancer and anxiety/depression as related. This third group of participants often described relationships as causal, with representations having both positive and negative influences on coping behaviours and self-management strategies. Representations were shown to change over the course of the cancer experience, with fear of cancer recurrence and the influence of participants' most challenging illness also discussed.

**Conclusions:** People hold multimorbid illness representations that can influence self-management. An awareness of these representations by researchers, health professionals, and patients is important for the creation of future interventions that aim to improve and maintain patient well-being.

**Keywords:** cancer; anxiety; depression; multimorbidity; illness representations

Anxiety and depression commonly occur as co-morbid illnesses in cancer patients. A meta-analysis of 60 studies (Massie et al., 2011) investigated the prevalence of co-occurring cancer and depression, estimating this co-occurrence at between 1.5 and 52%. Massie et al. (2011) suggested that this high variability in prevalence may be due to differences in the measurement of depression, different criteria used to define depression, and varying conceptualisations of depression (e.g., depression severity, depressed mood, minor depression, major depression, depressive disorder, adjustment disorder with depressed mood, and dysthymia), across the studies included in their meta-analysis. However, despite this range in prevalence, Massie et al. (2011) state that it is beyond doubt that cancer is associated with high levels of depression. Rates of anxiety amongst cancer patients vary, but some research suggests that anxiety accompanies cancer more frequently than depression (Mystakidou et al., 2005). For cancer patients, anxiety and depression are associated with poorer functioning (social and emotional) and quality of life (Mystakidou et al., 2005), with depression (both major depressive disorder and depressive symptoms associated with adjustment disorder) even found to predict elevated mortality in those with cancer (Pinquart & Duberstein, 2010; Satin et al., 2009). To improve the outcomes of people with co-morbid cancer and anxiety/depression, it is important to consider how they experience and think about their illnesses, and how these subjective illness representations are associated with coping and self-management behaviours.

One theoretical model that explores how patients' representations of their illnesses relate to coping and self-management is the Common Sense Model of Health and Illness (CSM; Leventhal et al., 1980). According to the CSM, when individuals perceive a health threat, they access cognitive and emotional representations of that threat based on their current experience, information from the external social environment and past illness experience, and general knowledge (Leventhal et al., 1980). These representations guide

peoples' coping responses and self-management strategies, and are appraised in terms of their success or failure in controlling the health threat and its consequences. Outcome appraisals then lead to the refinement of one's illness representations, as well as the selection of new coping/management strategies (Diefenbach & Leventhal, 1996). Being faced with more than one health threat or illness makes this process much more complex, with potential difficulties, such as misattributions of symptoms or conflicting self-management strategies, arising at each stage of the self-regulation process (Schüz, Wolff, Warner, Ziegelmann, & Wurm, 2014).

The key component of the CSM are illness representations; individuals' common-sense definitions of health threats (Leventhal et al., 1998; Leventhal et al., 1980), which guide individual coping attempts. A range of studies and meta-analyses underline the importance of these subjective representations for coping behaviours and illness outcomes in people with cancer (Richardson, Schüz, Sanderson, Scott, & Schüz, 2016), depression (Alderson et al., 2012), and mental illness (Baines & Wittkowski, 2013). However, only recently research has begun to examine illness representations in people with multiple illnesses. In a qualitative study on the content of illness representations and reported management strategies for people with multimorbidity, Bower et al. (2012) identified specific representations about multimorbidity, including medication burden, illness priority, and management synergies and antagonisms. In a second qualitative study (Mc Sharry et al., 2013), participants with co-morbid diabetes and depression either described their illnesses as unrelated with separate management strategies for each, or as being related, which in turn implied common treatment factors and interactions between the illnesses. Those participants who saw interactions between diabetes and depression often perceived one illness as causing the other (e.g., diabetes as causing depression), and accordingly described the management of both illnesses as either integrated or conflicting, e.g., in perceiving the symptoms of

depression to interfere with diabetes self-management. Participants also differed in the confidence (strength) with which they described multimorbid illness representations, with participants again also highlighting problems associated with medication burden.

Although these studies supported the CSM's general framework of illness representations guiding coping behaviours and self-management strategies, they also identified illness representations that were specific to multimorbidity, highlighting the need for more qualitative research in this area. Multimorbid illness representations are likely to vary across different illnesses, and examining the specific combination of cancer and anxiety/depression may give rise to additional insights into the representations of people with multimorbid illnesses. For example, cancer is a complex illness, with varying cancer types, stages of disease, and treatment types experienced by patients. Varying cancer types and stages mean that the severity of cancer differs widely between patients, with toxic cancer treatments such as chemotherapy associated with multiple side effects, and cancer-related surgery affecting issues such as body image. These factors are likely to influence representations of multimorbid anxiety/depression with cancer, and may provide distinct insights into how patients cope with and self-manage these illnesses. Cancer patients also commonly experience fear of cancer recurrence (FCR), a form of anxiety uniquely associated with fears or worries of a return or progression of a previous or new cancer (Lee-Jones et al., 1997; Simard et al., 2010). How FCR interacts with multimorbid representations, coping behaviours, and self-management strategies, could also provide important insights for this population. These unique issues associated with multimorbid cancer and anxiety/depression demonstrate the need for exploratory research within this population.

There is currently little existing research into the experience of multimorbid cancer and anxiety/depression, with much of the research instead focusing on: the role of anxiety/depression and cancer as separate illnesses for illness management, groups of cancer

patients without a formal diagnosis of anxiety/depression, anxiety/depression as assumed elements of the sequela associated with adjustment to cancer, or examining predictors of anxiety/depression in cancer patients. In addition, the majority of research that has assessed experiences of cancer and anxiety/depression has examined the coping behaviours and self-management strategies of each illness separately, rather than assessing them as integrated multimorbid illnesses. This study therefore is a first attempt to explicitly examine the experience of co-morbid cancer and anxiety/depression, rather than cancer and anxiety/depression separately.

By using semi-structured interviews, we aimed to address existing gaps in the literature by examining the content of illness representations and their associations with participants reported coping behaviours and self-management strategies for multimorbid cancer and anxiety/depression. Based on previous research by Mc Sharry et al. (2013), three key questions were used to guide this study. What kind of illness representations do individuals have for both cancer and anxiety/depression? Do all individuals think about the relationships between multiple illnesses in similar ways? Do particular illness representations facilitate different coping behaviours or self-management strategies?

## **Method**

### **Participants**

Participants were recruited via self-selection sampling through advertisements in local hospitals, in face-to-face support groups at Cancer Council Tasmania, and on appropriate Facebook pages (cancer support groups). Participants contacted the researcher and interviewer via phone or email and were invited to participate in the study if they met the following inclusion criteria: over 18 years of age, current or previous diagnosis with any type of cancer, current or previous experience with (diagnosed or treated for) anxiety or depression or both anxiety and depression.

Sample size was based on *information power* (Malterud, Siersma, & Guassora, 2015), a sampling criterion that addresses some of the limitations associated with the use of *saturation* (Glaser & Strauss, 2009; Malterud et al., 2015). Following the application of the information power criteria, 21 participants was considered an appropriate sample size, due to: the neither especially broad nor narrow study aims, the inclusion of participants specific to the research aim (based on meeting inclusion criteria), the study being supported by well-established theory (the CSM), the strong rapport and interview dialogue between the interviewer (ER) and participants (due to a strong knowledge of the theoretical background and previous experience working with cancer patients), and the use of cross-case analysis.

## **Materials**

Participants were required to complete a consent form, demographics and illness characteristics questionnaire, and the shortened version of the Depression Anxiety Stress Scale (DASS-21; Lovibond, Lovibond, & Psychology Foundation of Australia, 1995) to assess the current severity of the symptoms of each of these three negative emotional states. An interviewer guide that contained open-ended questions focusing on participant's experience of cancer, anxiety and/or depression, as well as illness representations (for individual illnesses and those relating to multimorbidity), and coping and self-management strategies, was used to guide each interview (see Appendix 4.1 for the full interview guide).

## **Procedure**

The study protocol was reviewed and approved by [withheld]. Participants were informed of the purpose of the study and the researchers' reasons for conducting it (to increase and improve understanding of cancer patients' thoughts and experiences) during contact. Although six participants were known to the interviewer through support work with Cancer Council [withheld], relationships were generally not established prior to study commencement. Following completion of the consent form, demographics and illness

characteristics questionnaire, and DASS-21 (Lovibond et al., 1995), face-to-face one-on-one semi-structured interviews were conducted by ER at either Cancer Council [withheld], the University [withheld], or in participants own homes. ER was a female PhD candidate in psychology with formal training and experience in support work with cancer patients. Interviews were audiotaped and lasted between 13 and 82 minutes ( $M = 50$  minutes), ending when all key topics had been covered. To maintain rapport and trust between interviewer and participant, no field notes were taken during interviews.

### **Analysis**

This study followed the Consolidated criteria for Reporting Qualitative research (COREQ) Checklist (Tong, Sainsbury, & Craig, 2007) (see Appendix 4.2). Interviews were transcribed verbatim and transcripts were imported into NVivo 10 qualitative data analysis Software (QSR International Pty Ltd., 2014) for ease of data management and thematic analysis. Participants were not given an opportunity to review interview transcripts as all information was de-identified to maintain confidentiality and ethical requirements.

Analyses were conducted from a subtle realist viewpoint, which involves acknowledging the subjective perceptions of researchers while attempting to represent the underlying existing reality under study (Mays & Pope, 2000). As this study was conducted within a CSM framework (with a particular focus on illness representations), our analysis was conducted under the a priori assumption that participants have representations about their illnesses. Based on recent research examining multimorbid illness representations (Bower et al., 2012; Mc Sharry et al., 2013), a theoretical thematic analysis was conducted (Braun & Clarke, 2006). This approach is used to provide a more detailed analysis of some particular aspect of the data, in this case differences in representations between those who identified links between cancer and anxiety/depression and those that did not. However, although a theoretical thematic approach was used, themes were not identified in advance but were



instead derived from the interview data, allowing for a richer description of that data.

Data analysis began with data immersion, which involved ER transcribing audiotaped interviews verbatim into written form and reading and re-reading completed transcripts to familiarise oneself with the data. ER then coded all transcripts into units of meaning using NVivo 10. Units of meaning were used rather than line-by-line, sentence, or paragraph blocks for coding, as predefined blocks of text may not accurately reflect meanings as intended by participants and important contextual information may be missed (Campbell, Quincy, Osserman, & Pedersen, 2013). To ensure reliability and to avoid missing important codes a second coder (JH) coded 5/21 (23.81%) interviews. Both inter-rater agreement (92.25%) and inter-rater reliability were good (Cohen's Kappa = .664) between ER and JH. Following coding, codes were collated into potential themes. Finally, themes were reviewed, cross-checked for overlap, defined, and named. Participants were not offered a chance to provide feedback on these themes, but instead could request to be sent any publications or research output arising from the research.

## **Results**

### **Demographics and Illness Characteristics**

Of the 22 participants who were met for interview, 21 were included in the study (3 males and 18 females), with one participant removed as they did not meet inclusion criteria (no diagnosis of or treatment for anxiety and/or depression). Participants were aged between 23 and 75 years ( $M = 50$  years,  $SD = 18$  years), with four participants experiencing anxiety, five participants experiencing depression, and 12 participants experiencing both anxiety and depression at some point throughout their lifespan. For more demographics and illness characteristics, as well as DASS-21 scores, see Table 4.1 and Appendix 4.3.

### **Thematic Analysis**

The main theme in the data was identified as representations of the relationships (or

Table 4.1

*Illness Characteristics and DASS-21 Anxiety and Depression Subscale Scores*

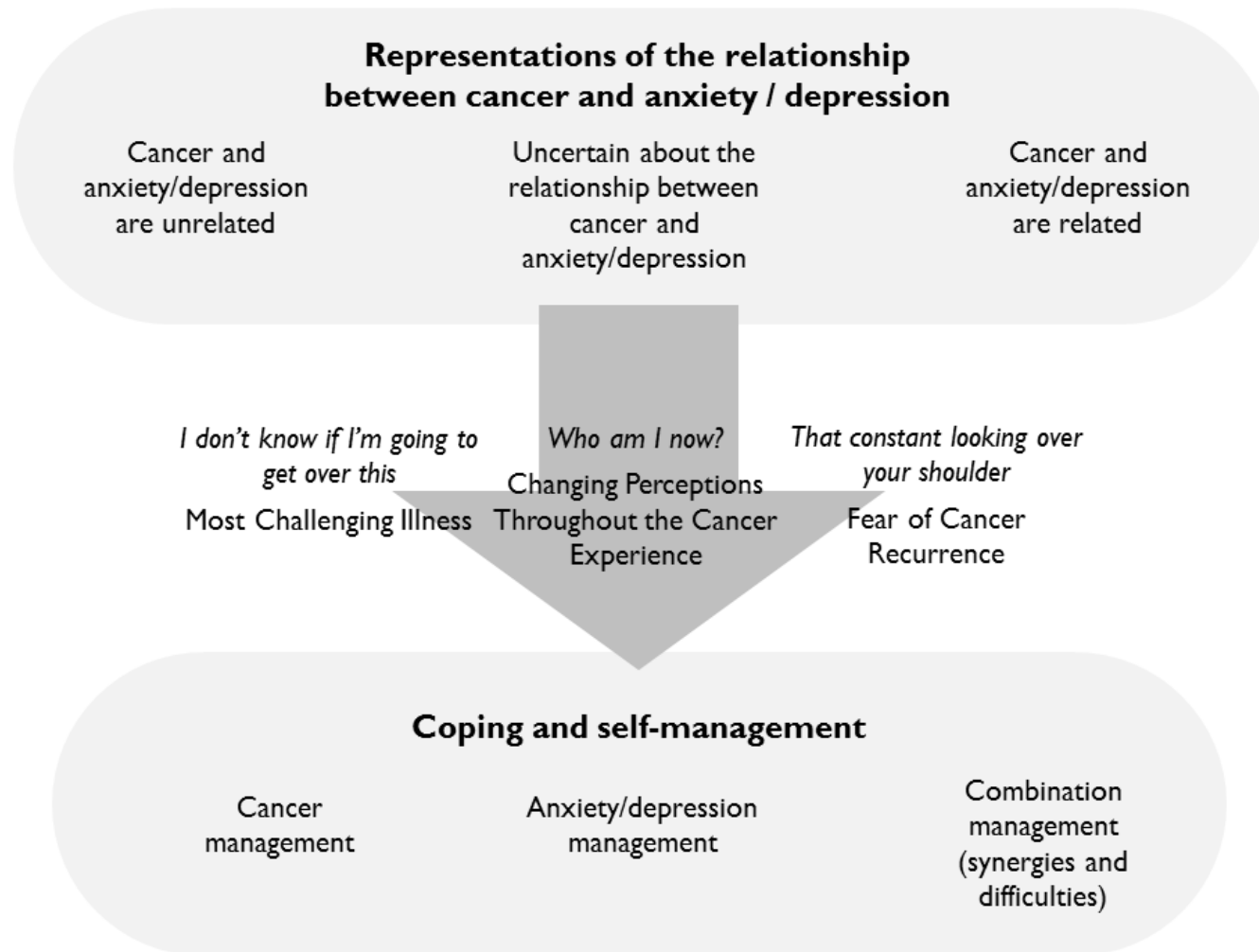
Characteristic	Characteristic Sub-Categories	N (%)
Primary Cancer Type	Breast	9 (42.9%)
	Bowel	5 (23.8%)
	Sarcoma	1 (4.8%)
	Hodgkin's Lymphoma	1 (4.8%)
	Non-Hodgkin's Lymphoma	1 (4.8%)
	Brain	1 (4.8%)
	Liver	1 (4.8%)
	Prostate	1 (4.8%)
	Unknown Primary	1 (4.8%)
Diagnosis of Second Primary Cancer	Yes	3 (14.3%)
	No	18 (85.7%)
Diagnosis of Secondary Cancer	Yes	4 (19.0%)
	No	17 (81.0%)
Cancer Treatment Stage	Peri-Treatment	5 (23.8%)
	Post-Treatment	16 (76.2%)
Cancer Treatment Type	Surgery	20 (95.2%)
	Chemotherapy	16 (76.2%)
	Radiotherapy	12 (57.1%)
	Hormone Therapy	6 (28.6%)
	Tablet Medication	7 (33.3%)
Order of Illness Diagnosis	Cancer pre- Anxiety	2 (12.5%)
	Anxiety pre- Cancer	11 (68.8%)
	Anxiety and Cancer Together	3 (18.8%)
	Cancer pre- Depression	5 (29.4%)
	Depression pre- Cancer	7 (41.2%)
	Depression and Cancer Together	5 (29.4%)
Other Multimorbid Conditions	None	9 (42.9%)
	One	9 (42.9%)
	Two	3 (14.3%)
DASS-21 Subscale	Subscale Ratings	N (%)
Anxiety	Normal	9 (42.9%)
	Mild	2 (9.5%)
	Moderate	3 (14.3%)
	Severe	2 (9.5%)
	Extremely Severe	5 (23.8%)
Depression	Normal	5 (23.8%)
	Mild	2 (9.5%)
	Moderate	2 (9.5%)
	Severe	2 (9.5%)
	Extremely Severe	10 (47.6%)

lack of relationships) between cancer and anxiety/depression, with these relationships guiding participants' coping strategies and illness management. This theme has been broken down for discussion into three sub-themes: 'cancer and anxiety/depression are unrelated', 'uncertainty about the relationship between cancer and anxiety/depression', and 'cancer and anxiety/depression are related'. How these representations influence coping and management will be discussed separately in each sub-thematic section. Three additional themes, fear of cancer recurrence, changing perceptions throughout the cancer experience, and most challenging illness, were found across representations of the relationships between cancer and anxiety/depression, and will be discussed as separate themes. Figure 4.1 presents a thematic map that provides a visual representation of results. To illustrate the main themes and highlight important issues, quotations will be presented. Demographic and illness characteristics will be provided where relevant, with pseudo-names used to preserve anonymity of participants.

### **Cancer and anxiety/depression are unrelated.**

Only three participants described cancer and anxiety/depression as unrelated. All three participants were female with very similar ages ( $M = 66$  years, range = 65-67 years), but had different cancer types (bowel, breast, and non-Hodgkin's lymphoma). All three participants had experienced depression pre-cancer, with two out of three also experiencing anxiety pre-cancer. The main reason for seeing no relationship between cancer and anxiety/depression was the perception of unrelated causes.

All three participants described causes for their anxiety/depression unrelated to cancer. For example, Ruby described the cause of her anxiety as workload with additional links between anxiety, genetics, and low self-esteem. With regard to depression, Ruby proposes it 'is actually triggered by events' (although not by her cancer diagnosis), while also describing links between her anxiety and depression 'there's anxiety which is leading to



*Figure 4.1.* Thematic map of representations of cancer and anxiety/depression and their relationships with coping and self-management strategies.

depression’.

Coping and self-management in participants who perceived no relationship between cancer and anxiety/depression varied. For Julia, there was no overlap between the management of depression and cancer, with depression only managed through the use of antidepressants, while cancer was managed by trying to ‘keep life as normal as possible’ through activities such as walking and visiting friends and family. For both Ruby and Bridget, similar self-management strategies were used for both cancer and anxiety/depression (e.g., distraction through social support, making music, or reading [Bridget]), though no explicit links were made about managing these illnesses in tandem. Ruby, however did identify some links between mental and physical health, in that when feeling anxious or concerned, things like posture and diet deteriorate, leading to poorer health. According to Ruby ‘if you can catch that and you just get it right, then you physically feel better.’.

#### **Uncertainty about the relationship between cancer and anxiety/depression.**

Five participants did not describe clear relationships between cancer and anxiety/depression. Participants in this group varied in age, gender, and cancer type, though four out of five participants experienced their depression and/or anxiety pre-cancer. Two participants, Bonnie and Janet, considered cancer as a potential cause for their depression, while another two participants, Adam and Mary, considered anxiety/depression as a potential cause for their cancer. However, all four of these participants mentioned alternate causes they had also considered. For example, Bonnie did not mention cancer as a cause for her depression originally, when questioned specifically she suggested the physical consequences of the cancer and its treatment may play a part in causing her depression, ‘this can come over me, um, if it’s been particularly difficult, if I feel like, that um, it’s restricted my life too much.’.

One participant, Matthew, did not perceive any causal links between depression and

cancer and was not depressed at the time of his cancer, but did highlight how having cancer made it more difficult to cope with underlying depression.

I wasn't depressed at the time I had cancer. (ER: Mmhm). Um, I was in a really good space. Um, but it definitely sort of having something like that happen makes everything a lot harder ... Like it didn't make me depressed but I, it was definitely a lot more of a struggle because it happened. (Matthew)

Matthew also identified how having a predisposition to depression made it more difficult to cope with cancer.

It definitely made it harder, because you know, you struggle to cope with things, and you know like I said those coping mechanisms that you have, if you can't do those, like you, they're in place for a reason and you do them for a reason. (ER: Mm.). Um, especially when you're, you're sick and stuff and you can't do those. It, it did, you know, have an impact. (Matthew)

The other four participants had fairly distinct coping and self-management strategies for cancer and anxiety/depression, with this mostly due to the timeline of development for each illness (fairly distant) and the different causal factors for each illness.

### **Cancer and anxiety/depression are related.**

The remaining 13 participants described relationships between cancer and anxiety/depression, with these relationships often considered causal.

#### ***Anxiety/depression causes cancer.***

Four participants described anxiety/depression as a cause for their cancer, with, for example, Samuel suggesting depression was the cause of his cancer, 'I believe, honestly that I got it through depression and stress.' Sophie, who developed depression following the passing of her mother, believed that depression may have helped her cancer to grow.

The depression would have helped the cancer, well it would have helped the cancer grow, um I would think. Um, because it has to be expressed somehow. I think when you internalise stuff, uh, in that way, um. Because we're very good at talking about things that make us happy and our joys, but not the other, we keep it in, it must, and it has to come out some way surely. (Sophie)

#### ***Cancer causes anxiety/depression.***

The remaining nine participants described the opposite relationship, with cancer believed to be a direct cause for their anxiety/depression: 'I'm anxious because I have cancer,

yes' (Anna), or 'I think the cancer caused the depression, yes.' (Georgia).

Another common point of discussion across participants was that the consequences of cancer (symptoms, treatment side-effects, etc.) were linked with causing or influencing anxiety/depression. Participants suffered from a wide range of cancer-related consequences that were perceived as causing anxiety/depression, including visible scars from treatment, physical disabilities, hair loss, inability to work, fertility difficulties, and loss of independence. For example, Sarah, who had a brain tumour (Medullablastoma) and needed extensive treatment including surgery, chemotherapy, and radiotherapy, described several permanent physiological consequences from her cancer and its treatment. She described these consequences and the resultant loss of control as the main reason for her anxiety and depression.

When I started feeling depressed, um, was, I guess when I lost my hair ... when I realised how much of my life I'd, that I've lost control of. Because when I was, um, younger, like when I, like I couldn't, I could always have an escape. (ER: Mm.). Like, you know, even through work, or you know, working really hard, thinking to myself, "well I'm going to be able to make myself better, or I'm going to be able to get over, get above this" ... because I had control. ... and then going from that type of person to losing my hearing, losing my hair, confidence, the ability to be independent, and not working... (Sarah)

***Cancer, anxiety, and depression are intertwined.***

Several participants suffered from cancer and both depression and anxiety, with some of these participants suggesting that all three illnesses were intertwined. For example, Sarah suggested that for her 'Anxiety brings on depression, and cancer brings on anxiety. It is really just a ball ... It's just a rolling ball.'. When relationships were perceived between cancer and anxiety/depression, attempting to cope with and manage them was described as being more difficult than dealing with one illness alone, with several participants, including Lisa, describing this challenge.

ER: So having all three of those, how much harder did that make things? Lisa: Oh it was excruciating. Just even the needles for my chemo, my anxiety... I used to have a double dose on my anxiety pills before they tried to put a needle in. (ER: Mm.). Um, and being a needle-phobe doesn't help, but the anxiety was always sky high when I walked into the hospital. So I would pop a pill in the car on the

way in, then in the waiting room I'd pop another one, so that's double dosing. (ER: Mm.). Um, and even then it was a struggle for them to get a line in. So, it was... I, it just made everything that much harder. ... Even just going to an appointment with the oncologist and she'd talk about what she'd found. What the diagnosis was. What, you know, what the cancer ... That was really hard. (ER: Mm.). Um, and then I'd leave there and, and I'd sink into the biggest, um, a funk, you know. (Lisa)

***Coping and self-management strategies.***

Although cancer and anxiety/depression were seen as related by the majority of participants, this did not necessarily mean that these participants used strategies to help cope with and manage their illnesses together. Quite often, separate self-management strategies were utilised for each illness. However, some participants highlighted that managing one aspect of an illness may be of benefit to their other illness. For example, Cheryl, who had metastatic breast cancer, explained how meditation and relaxation was not only beneficial for reducing her anxiety, but also for helping to heal her body.

However, several participants also described how interactions between cancer and anxiety/depression can negatively impact coping and self-management. For example, at times it can be difficult to determine the best way to manage a particular symptom, particularly when it is unclear whether it is a symptom of the cancer, a treatment side-effect, or a symptom of anxiety/depression.

Um, depression yeah. When you've got that foggy state in your mind and you're fatigued and your treatment, it, it can be really really hard to motivate yourself. But it's more a, I'm not sure how much it's treatment related or (ER: Mm.) what it, it's just really hard to, sort of, um. I sort of feel when I'm being down and crap and stuff like that I just thinking, "ok I probably am depressed" but I just think "ok these are going to be the side effects of the treatment that I'll need to work through", and yep. (Cheryl)

Further for some participants with anxiety/depression, the symptoms of cancer or the side-effects from cancer treatment prevented them from being able to participate in their normal anxiety/depression coping strategies. For example, Matthew described the importance of exercise, specifically running, as a coping strategy for depression (or to keep depression dormant), 'So exercise is normally a massive one for me ... If I don't, you know, I just go



downhill really quickly’. However, after his diagnosis of liver cancer, surgery and chemotherapy were required, limiting his ability to exercise, and requiring him to find other coping strategies.

Similarly, some participants suggested that the symptoms of anxiety/depression prevented them from undertaking either their usual cancer prevention strategies, or general lifestyle and health factors that are known to help prevent cancer. For example, Mary stated that in the past her depression had prevented her from ‘yoga and gym and horse riding and rowing and going out of walks’, while Lisa explains how the consequences of her depression prevent her from doing the healthy living practices that she knows will help to prevent future cancer.

Not eating the healthy foods that I know are going to protect me from future cancer. (ER: Yes.). But eating the comfort foods that are undermining my whole health plan. Um, also the inability to go out and do exercise. (ER: Mm.). Um, because gentle walking is my chosen form of activity. ... But when I’m feeling depressed do you think I can walk out that door? (ER: Mm.). Nup. ... We came to the country for lifestyle... (ER: Yes.) for fresh air, to grown our own fruit and veg, to have healthier food, all that sort of stuff. (ER: Yes.). And when I give in to the depression, it undermines everything. (ER: Mm, mm.). I don’t look after my family properly. I don’t look after myself properly. (Lisa)

### **That constant looking over your shoulder - Fear of cancer recurrence.**

One particularly important issue that is fairly unique to the cancer space and arose commonly when discussing the relationship between cancer and anxiety, was fear of cancer recurrence for those post cancer treatment (FCR; Lee-Jones et al., 1997; Simard et al., 2010). FCR is common but can become problematic when it influences behaviour. Most participants mentioned some experience of FCR, particularly around check-ups, tests, or scans.

‘You worry at times. (ER: Yes.). When, when you come up to the six monthly pathology I still. “ah here we go again”, you know (ER: Mm.) sort of thing ... And it’s a bit of anxiety there, but nothing that you don’t cope with and handle.’. (Adam)

However, several participants described experiences of FCR at a more debilitating level. For example, Rebecca described the constant focus on any abnormality or discomfort she noticed within her body post cancer.

An ache or pain is never just an ache or pain to me, it's always like, could it be more. (ER: Mm.). ... Whereas most people get an ache or pain they wouldn't even think of cancer... (ER: Yes.) would be the furthest thing from their mind. But for me, every ache or pain could be that. (Rebecca)

For participants like Danielle, this constant FCR led them to experience depression.

I lived on this level of anxiety for quite a while, quite a high level, without realising that's what it was. (ER: Mm.). And it just tires you out. And then you get depressed, because you, yeah, you're tired and you lock yourself in the house, and you don't get out of bed because you're scared you're gonna hurt yourself. (Danielle)

Several participants also described how this constant FCR also drove particular coping behaviours and self-management strategies, not all of which were adaptive. Examples of these behaviours included adjusting eating behaviours and food choices, taking multiple dietary supplements, constantly searching the internet 'engrossed in Dr Google', and making constant calls or visits to previous or current treating health professionals.

Um, basically cause after the treatment was finished I was like always at the Doctors. Like I'd always be going back to the GP. I would go, "I've got a pain in my elbow"... (ER: Yeah.). and I would, you know that was like a classic example, "I have a pain in my elbow, like I must have cancer in my elbow". (ER: Mm.). And he's going "no", you know, check me elbow out, "it's fine". By the time I'd walk back to the car, this pain I'd had for a couple of weeks had gone. (Rebecca)

I could be perfectly fine in the morning, and I'd bump my knee, and by lunch time I would have cancer in my knee and in my bones, and I'd be ringing the oncologist and saying I need a bone scan. And you know, and I just bumped my knee! But that's where it took me. ... And they're still there. That's my first thought. It's still there. (ER: Mm.). Every time something hurts. I was driving home from Burnie yester, last night. And the front of my shoe was hurting, and I had to keep rubbing it. It was quite sore. (ER: Mm.). And I was thinking, "Oh God, I've got cancer in my bones now. Oh Danielle don't be an idiot. It's just a strain from the accelerator for the last four and a half hours." Like, you know, it's gone today. \*Laughs\*. (Danielle)

### **Who am I now? - Changing perceptions throughout the cancer experience.**

An additional theme arising related to changing self-perceptions throughout the cancer experience and how these interact with experiences of anxiety/depression, as well as coping and self-management. In having such a large impact on one's life, it is unsurprising that many participants described cancer as leading to changes in perceptions, self-image, attitudes, and opinions. For several participants these changes were positive, with Melanie

describing improvements in her attitude towards work and Bridget describing changes to how her and her partner live their lives, ‘we don’t hold off ... either in terms of doing this or enjoying things, or even saving money ... you know, now is when we need to do it’. However, at times these changes presented challenges for participants, particularly when related to changes in self-image.

And looking in the mirror at myself and saying, “That’s not you... You didn’t...” I looked like you before, more or less. A lot older obviously, but long blonde hair. (ER: Yeah.). Had all my life been someone with long blonde hair. And then suddenly I’m not that person anymore. (ER: Mm.). And probably will never be the person that I was before. (ER: Mm.). So it’s kind of dealing with that too. Who am I now? (Kathryn)

Changes in self-perception were often associated with experiences of loss and grief. For example, Georgia described how cancer led to a ‘loss of sense of identity because it’s changed who I am as a person. It’s changed the way I view myself, and my self-image ... and the way I view the world.’. This loss was particularly evident amongst participants with metastatic cancer, who had been required to face their mortality at a deeper level.

I was doing really well. ... We’d had Amelia, I’d returned from maternity leave, I was getting back on track with work, we were considering having another child, I’d gone off the pill, you know, we were at that sort of stage of our lives, and... that’s all sort of gone. ... I feel like things have been taken away from me. And, to start off with a lot of it was grieving the life that we were going to have. Because I had to stop thinking, planning. ... I wasn’t able to plan at all. ... I didn’t feel like I wanted to plan six months ahead. ... My husband wanted to go sort of do like a bucket list thing, and let’s tick everything off, let’s do all the things that we would have done in, in the future, but I couldn’t even do that cause I didn’t want it to be like the last hoorah, “ok we’re going to travel and then I can die after that”. (Anna)

Associated with these perceptions of loss and grief, were representations around normality. Several participants, including Julia, mentioned trying to ‘keep life as normal as possible’ as one way of coping with their cancer. While other participants, like Mary, realised that life ‘might not ever be the same again’. Lori described not remembering ‘what it’s like to have a normal life’, while Lisa explained ‘There is no life as normal.’. Some participants also described having to learn to accept their ‘new normal’, while others struggled with family or friends who believed that they should be ‘back to normal’ post-

treatment.

And he thinks that now that I don't have to see the doctors for twelve months that things are back to normal. But I'm thinking "well, normal for me is different.". (Melanie)

### **I don't know if I'm going to get over this - Most challenging illness.**

Some participants suggested that anxiety/depression were more challenging than cancer. This was particularly true amongst participants who had recurring or chronic anxiety/depression and/or who had completed treatment for, or were in remission from, their cancer. Participants described several reasons for these beliefs, including a more chronic or cyclical timeline for anxiety/depression, less control over anxiety/depression, and less understanding of anxiety/depression. Julia highlighted how the more chronic nature of depression makes it more challenging to cope with, 'the cancer diagnosis, treatment, bla, bla, bla, that's all over now. (ER: Yes.). Whereas the depression will go on forever'. When describing why depression was more challenging for her, Sophie highlighted her lack of understanding of depression, as well as the absence of the depression label.

I think on reflection the depression is harder. ... Because it wasn't named. I was just living in a particular way. (ER: Mm.). Ah, whereas the cancer it's named. It's like, you can do something with that if you so choose. (ER: Mm.). And because medicine is such, then there are things that can happen to help that. Um, and I've always, I always think that the knowing, knowing something is better than not knowing. (Sophie)

Several participants, including Danielle, described struggling with anxiety/depression because of a lack of control over their illness, 'The anxiety is probably the hardest to deal with, to be honest. ... When it's not under control, it just has such a debilitating effect.' Adam described a similar lack of control, 'Anxiety's something in there that, almost out of your control. (ER: Mm.). You've got to really, really work harder, to control it, than what you do to cope with the facts of having cancer.' Although Lisa described both cancer and depression as extremely challenging, she explained that depression, at its worst, was more difficult than cancer, as it led to her losing the will to live.

Well... cancer was really, really, really hard. Um, because it, it's physical inside you. (ER: Yes.). ...

See with cancer, I wanted to live and that's why I let them poison me... (ER: Mm.) that's why I let them stick needles into me, and that's why I went through all of those things is because I wanted to live. But when I was at my worst with depression I wanted to die. ... So perhaps depression was... at its worst... was harder than cancer. ... I think the thing with cancer is you can see the light at the end of the tunnel. 'Cause you know these are the steps you've got to go through before they tell you that your treatment's finished. (ER: Yes.). You, you know what's coming. But with depression you don't. ... It's almost like, you know, even when you're feeling good you know that somewhere it's just lurking. (Lisa)

In contrast, several participants, including all four participants with metastatic cancer, described cancer as more challenging than anxiety/depression. The life-threatening nature of cancer, particularly metastatic cancer, as well as a lack of control over cancer, were described as the main reasons for perceiving cancer as participants most challenging illness. Mary, who was recently diagnosed with Stage IV bowel cancer, provided a clear insight into how cancer stage and the life-threatening nature of metastatic cancer can influence perceptions of cancer.

I have stage four cancer... (ER: Mm.). I'd rather be depressed again and not have cancer. I can get over the depression... (ER: Mm.) and then be... live 'til 80, please. Um, but if I had stage one cancer, maybe I'd answer differently. (ER: Mm.). Cause as I said, especially early on in my diagnosis I kept thinking "this is going to be quick fix and over and move on with life." (ER: Yes.). So if I felt, if I still felt like that, then maybe I'd answer differently. But as a stage four cancer person absolutely 100% I would rather be depressed than have cancer, because I can, I know I can get over depression ... but I don't know if I'm gonna get over this.

## Discussion

This qualitative study aimed to examine multimorbid illness representations and their associations with coping behaviours and self-management strategies in people with cancer and anxiety/depression. Our findings suggest that patients think about the relationships between multiple illnesses in different ways, with some viewing cancer and anxiety/depression as unrelated, some unsure about the relationship between cancer and anxiety/depression (think that there could possibly be a connection between them), and some viewing cancer and anxiety/depression as related. We also found that participants' representations had clear links with coping and self-management behaviours.

Three participants perceived cancer and anxiety/depression as unrelated, with all three

participants experiencing anxiety/depression pre-cancer. These participants did not discuss links between cancer and anxiety/depression, instead discussing alternative causes for their mental illness/es. Further, two participants described a lack of understanding of their illnesses, particularly demonstrating confusion regarding the difference between anxiety and depression. Finally, although two participants mentioned using the same coping behaviours and self-management strategies for both cancer and anxiety/depression, no explicit links were made between these strategies.

Five participants were uncertain about the relationship between cancer and anxiety/depression, with four participants describing multiple potential causes for either cancer or anxiety/depression (including cancer or anxiety/depression itself). This indicates a lack of understanding about the causes of cancer and anxiety/depression. For these participants, coping and self-management behaviours were different for each illness, and this appeared to be mainly due to the distant timeline between diagnoses. Although one participant suggested no causal relationship between his cancer and depression, he did describe how cancer had made it more difficult to cope with underlying depression, and how underlying depression had made it more difficult to cope with cancer.

Similarly to a previous study of diabetes and depression (Mc Sharry et al., 2013), the majority of participants (13) described relationships between their illnesses. In general, these participants described either causal links between cancer and anxiety/depression, how consequences of cancer and its treatment caused anxiety/depression, or how cancer caused fear of cancer recurrence (FCR) related anxiety, which at times then led to depression. For these participants, the type of links described influenced the coping behaviours and self-management strategies undertaken. For example, for those whose cancer had led to FCR, coping and self-management strategies that ease this fear were frequently described, including adjusting eating behaviours, taking dietary supplements, using the internet to search

for health information, or making constant calls or visits to treating Doctors. In our interviews, the strategies described were often maladaptive, suggesting the need for appropriate intervention. Similarly to previous research (Bower et al., 2012; Mc Sharry et al., 2013), both separate and combination coping and self-management behaviours were described, with behaviours beneficial to both illnesses employed at times, while symptoms or side-effects of one illness were sometimes suggested to prevent normal coping and self-management strategies for the other illness. Interestingly, in contrast to previous research (Bower et al., 2012; Mc Sharry et al., 2013), issues in managing multiple medications were rarely described.

Both within and between participants, changing perceptions and needs throughout the cancer experience were described, suggesting that different representations may be present at different stages of illness timeline, and that these representations may need to be re-assessed and modified depending on content and adaptability. This was also true with respect to coping behaviours and self-management strategies, which varied across different timelines and stages of illness. These findings provide support for the CSM's feedback loop, which suggests that individuals act as problem solvers who constantly appraise their coping/self-management behaviours and change illness representations accordingly, leading to the adoption of new management strategies (Leventhal et al., 1998; Leventhal et al., 1980). However, longitudinal studies are required to gain a more systematic understanding of specific changes in multimorbid illness representations and their associations with coping behaviours and self-management strategies.

Several participants described anxiety/depression as more challenging than cancer. These participants were often sufferers of recurring or chronic anxiety/depression and/or in remission from their cancer. Reasons for the more challenging nature of anxiety/depression was related to representations of a more chronic or cyclic timeline for anxiety/depression, less

control over anxiety/depression, and less understanding of anxiety/depression. In contrast, several participants described cancer as more challenging than anxiety/depression.

Importantly, all four participants with metastatic cancer were included in this group. Reasons for the more challenging nature of cancer included perceiving less control over cancer, and beliefs about the life-threatening nature of cancer. A lack of control was identified as an important factor for participants no matter which illness they described as most challenging, with less perceived control associated with a range of coping behaviours and illness outcomes (Richardson et al., 2016). Perceived control is also associated with the use of varying self-management strategies, such as decision making and priority setting (Bratzke et al., 2015). Although not always inaccurate (particularly for those with metastatic cancer), control beliefs may be important to target in interventions, as they continually appear as important predictors of coping, self-management, and mental health.

Research suggests that patients will prioritise a dominant chronic illness (Bratzke et al., 2015), and therefore it may be beneficial to add additional items that assess participants most challenging or dominant illness to questionnaires such as the Illness Perception Questionnaire (Moss-Morris et al., 2002; Weinman et al., 1996). If patients state one illness as more challenging than another, it may be possible to determine which individual illness representations are more likely to be determinants of behaviour. However, due to the changing nature and re-prioritisation of representations over time (Bratzke et al., 2015), the potential for these beliefs to be unstable must be considered before attempting to rely on their content in an intervention.

## **Limitations**

Due to the lack of existing research examining illness representations in people with cancer and anxiety/depression, qualitative methods were used to explore such representations. A limitation associated with the use of qualitative methods is the potential for



the subjective perceptions of researchers to unknowingly influence the analysis. However, in conducting this study from a subtle realist viewpoint, our subjective perceptions were constantly acknowledged while we attempted to represent the existing reality under study (Mays & Pope, 2000). The possibility of recall bias by participants must also be considered as a potential limitation in qualitative research.

The study lacked measurement of crude diagnostic indicators, such as whether participants had ever been hospitalised or had outpatient contact for clinical depression or anxiety. Further, although we recruited participants who had received either a formal diagnosis or previous treatment for anxiety/depression, there was no clear differentiation between those with major depression and those with ‘normal’ psychological distress associated with the cancer experience.

Our participant sample varied widely in terms of cancer type, cancer stage, and treatment type, with this heterogeneity likely responsible for variations across some results. For example, the results of the DASS-21 found that although our sample had an almost even number of participants who had experienced depression/anxiety (four with anxiety only, five with depression only, and 12 with both anxiety and depression), there were large differences across anxiety and depression scores, with 42.9% of participants experiencing normal anxiety in comparison to 23.8% experiencing normal depression, and 23.8% of participants experiencing extremely severe anxiety in comparison to 47.6% experiencing extremely severe depression. It is possible that more consensus might have been found by using a more focused sample, for example by only interviewing participants with breast cancer, or by only interviewing participants with Stage I (early-stage) disease. In contrast, additional insights might have been uncovered with the inclusion of a more diverse sample. For example, our sample only included three males, making meaningful gender differences difficult to examine. Despite these potential limitations, our sample was able to provide both overlapping

and unique representations, suggesting a good mix between specificity and diversity.

## **Implications**

This study identified a number of multimorbid illness representations, including differing representations of relationships between cancer and anxiety/depression, fears of cancer recurrence, participants' identification of their most challenging illness, and changing beliefs across the illness experience. This suggests that standardised assessments of illness representations such as the illness perception questionnaire (Moss-Morris et al., 2002; Weinman et al., 1996) might not be applicable for multiple illnesses, but would need adaptation (e.g., C. J. Gibbons et al., 2013; Mc Sharry, Bishop, Moss-Morris, Holt, & Kendrick, 2015). Such adaptations may lead to an increased understanding of determinants of current behaviours, as well as the implementation of more appropriate treatment approaches by health professionals.

The CSMs illness representation dimensions have been used increasingly in interventions for single illnesses. These intervention trials have shown positive results, with more accurate illness representations, increases in illness coherence and perceived control, improved mental health, and participation in more positive self-management strategies adopted (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009; Petrie, Perry, Broadbent, & Weinman, 2012; Siemonsma et al., 2013). Interventions for patients with multimorbidity could potentially use a similar approach to the interventions that have been trialled for single illnesses, though modifications to take into account the more complex nature of multimorbid representations would be required. For example, combined or competing representations, prioritisation of a more challenging illness, and changing representations over time, would need to be considered before a comprehensive intervention program could be implemented.

People with multimorbid cancer and anxiety/depression require more support, with research demonstrating that oncologists are often poor at recognising distress and the need for

further counselling in their patients (Söllner et al., 2001). However, in recognising such needs, health professionals should not always assume that anxiety/depression is specifically related to the cancer experience or adjustment process. Education for health professionals regarding the content of patients multimorbid illness representations, as well as the importance and impact of multimorbidity, particularly with respect to cancer and anxiety/depression, is important for improving patient outcomes. Health professionals should also be educated about the benefits of combination management strategies, where health behaviours such as exercise or mindfulness can lead to improved patient outcomes across multimorbid illnesses (Ledesma & Kumano, 2009; Mishra, Scherer, Geigle, et al., 2012; Mishra, Scherer, Snyder, et al., 2012). However, for these strategies to be successful, care must be taken to ensure that participants multimorbid illness representations are congruent with their implementation. Finally, health professionals must be made aware of the ongoing challenges that cancer survivors and metastatic cancer patients face, with patients often requiring assistance to accept their ‘new normal’.

## **Conclusion**

This study provides support for the CSM as an effective basis for exploring patients multimorbid representations, with differing illness representations of, and management strategies for, cancer and anxiety/depression identified across participants. However, although specific illness representation dimensions from the CSM have been used in interventions for single illnesses, the experience of multimorbid illnesses cannot currently be fully addressed by the CSM, with a need to consider additional and more complex representations. Future research should attempt to confirm whether representations identified in this study can help to inform intervention design for cancer and anxiety/depression. If a clear understanding of patients’ multimorbid representations can be gained, it may help to improve health care interactions, as well as the coping behaviours and self-management

strategies, of those with cancer and anxiety/depression.

## Chapter 5

### Study 4

#### **A qualitative comparison of the support needs of people with cancer based on their history of anxiety/depression\***

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\*Richardson, E. M., Scott, J. L., Schüz, N., Sanderson, K., & Schüz, B. (2016). *A qualitative comparison of the support needs of people with cancer based on their history of anxiety/depression*. Manuscript submitted for publication.

### Abstract

**Purpose:** Research rarely considers the origin or history of a cancer patient's anxiety and/or depression, instead assuming that these illnesses are related to the cancer experience. The aim of this study was to compare differences in the support needs of people who have experienced anxiety/depression as part of the cancer experience and people who have not, as well as between people who have experienced episodic anxiety/depression and people who have experienced long-term anxiety/depression.

**Methods:** Twenty-one semi-structured interviews were conducted with people with a current or previous diagnosis of cancer, and a current or previous experience with anxiety and/or depression. Participants were split into four groups based on their history with cancer and anxiety/depression, and an inductive thematic analysis was conducted to identify themes across groups.

**Results:** Two superordinate themes (with three and two subordinate themes respectively) were found: 'coping with cancer' and 'health care system support provision'. Important differences were found across groups, with participants in Group 4 (who had long-term anxiety/depression and whose anxiety/depression was not associated with the cancer diagnosis) coping best with cancer, experiencing less fear of cancer recurrence, and highlighting more positive experiences with hospital and support services.

**Conclusions:** The origin and history of a person's anxiety/depression is important to consider when determining how they might cope with cancer, what their support needs are, and how much support they may require during the diagnosis, treatment, and survivorship phases of cancer.

**Keywords:** cancer; anxiety; depression; co-morbidity; support; needs

Traditionally, psycho-oncology has examined anxiety and/or depression as conditions resulting from the cancer experience (Pasquini & Biondi, 2007). However, not all people with cancer develop anxiety/depression, and their levels of distress vary (Helgeson et al., 2004; Henselmans, Helgeson, et al., 2010). Further, some people have pre-existing anxiety/depression which then becomes co-morbid with cancer, while others experience episodes of anxiety/depression that occur in response to significant life events (including the cancer diagnosis). These examples highlight that anxiety/depression experienced by someone with cancer can have differential aetiology. However, the role of these origins and how they influence the cancer experience and the support needs of people with cancer and anxiety/depression is rarely considered in psycho-oncology research (Jacobsen & Jim, 2008; Pasquini & Biondi, 2007).

The most important areas in need of support for people with cancer include physical health and daily living, psychological health, health system and information, and social support (Harrison et al., 2009). Although there are several interventions aimed at addressing these needs, a recent review has found that such interventions generally have limited effectiveness (Carey et al., 2012). Further, though much of the research and interventions for people with cancer aim at improving distress, and one study has specifically examined how screening for distress might uncover unmet needs in people with cancer (van Scheppingen et al., 2011), research so far has not taken into account whether needs differ according to which illness (cancer or anxiety/depression) came first, or the causes of anxiety/depression. It is therefore unclear whether and how the needs of people with cancer are influenced by their history with anxiety/depression.

Comparing the support needs of people with varying histories of cancer and anxiety/depression will allow us to identify and discuss how the potentially differing needs of people according to their cancer and anxiety/depression history can best be addressed. For

example, those who have experienced anxiety/depression as part of the cancer experience might differ from those who have not, and those who have experienced episodes of anxiety/depression in relation to significant life events might differ from those who have experienced long-term anxiety/depression. Support needs may differ between these groups, as long-term depression tends to be clinically more serious, is more often co-morbid with anxiety, requires more treatment, and leads to poorer social and psychological outcomes and reduced well-being, than episodic depression (Angst et al., 2009). Examining differences between these groups is important because although intervention studies often take into account psychological distress at baseline (Schneider et al., 2010), they rarely consider how a prior history of anxiety/depression may influence intervention effectiveness. Further, the outcomes of interventions for cancer patients with distress are often mixed, and previous systematic and meta-analytic reviews yielded disparate conclusions that are often difficult to interpret (Galway et al., 2012; Jacobsen & Jim, 2008; Lepore & Coyne, 2006). This highlights the need for more research on how the aetiology and sequence of cancer and mental illness may determine the support needs of people with cancer and anxiety/depression. This knowledge can form the basis for better targeted and more effective interventions, as well as improved access to appropriate support services, for people with cancer and anxiety/depression.

This study therefore aims to explicitly examine and compare the existing supports and needs of people with cancer and different histories of anxiety/depression (e.g., episodic versus long-term) through semi-structured interviews, allowing for insights to be gained through thematic analysis without researcher preconceptions. Two key questions were used to guide this study:

1. How do different histories of anxiety/depression influence the support needs of people with cancer?



2. How can support providers and health professionals better assist people with cancer and anxiety/depression based on their history with each illness?

## **Method**

### **Participants**

Twenty-one participants was considered an appropriate sample size for this study based on *information power* (Malterud et al., 2015). Information power provides clear criteria for ascertaining appropriate sample sizes in qualitative research while addressing some of the limitations associated with the use of *saturation* (Glaser & Strauss, 2009; Malterud et al., 2015) (see Appendix 5.1). Participants were recruited via self-selection sampling through advertisements in Cancer Council Tasmania face-to-face support groups, local hospitals, and appropriate Facebook pages (cancer support groups). Persons interested in participating contacted the researcher via phone or email and were then invited to participate in the study upon meeting the following inclusion criteria: over 18 years of age, current or previous diagnosis with any type of cancer, current or previous experience with (diagnosed or treated for) anxiety or depression or both anxiety and depression. Ethics approval was obtained from the Tasmanian Human Research Ethics Committee (H0014664).

### **Materials**

Participants completed a consent form, demographics and illness characteristics questionnaire, and the shortened version of the Depression Anxiety Stress Scale (DASS-21; Lovibond et al., 1995) to assess the symptom severity of each negative emotional state. An interviewer guide with open-ended questions was used to direct each interview (see Appendix 4.1).

### **Procedure**

Face-to-face one-on-one semi-structured interviews were conducted following completion of the consent form, demographics and illness characteristics questionnaire, and

DASS-21 (Lovibond et al., 1995). The first author conducted each interview (ER; female PhD student with formal training and experience in support work with cancer patients) at a place convenient to participants (university, Cancer Council, or participants' homes). Audiotaped interviews lasted between 13 and 82 minutes ( $M = 50$  minutes), ending after all key topics were covered. For additional methodological information see Appendix 5.1.

### **Analysis**

This study followed the Consolidated criteria for Reporting Qualitative research (COREQ) Checklist (Tong et al., 2007; see Appendix 5.2). Following verbatim transcription, transcripts were de-identified and imported into NVivo 10 (QSR International Pty Ltd., 2014) for data management and thematic analysis.

A subtle realist viewpoint guided analyses, where the researchers' subjective perceptions were acknowledged while attempting to represent the underlying existing reality under study (Mays & Pope, 2000). An inductive thematic analysis was conducted (Braun & Clarke, 2006). This approach involves a data-driven way of identifying themes, where data is coded without any pre-existing coding frames or researcher preconceptions. Thematic analysis was guided by Braun and Clarke (2006), who provide clear steps for conducting such an analysis.

Data analysis began with data immersion (ER transcribing interviews and reading completed transcripts several times to familiarise with the data). All transcripts were then coded into units of meaning by ER using NVivo 10. Units of meaning were used for coding, as predefined blocks of text (lines or sentences) may inaccurately reflect intended meanings of participants and important contextual information may be missed (Campbell et al., 2013). A second coder (JH) coded 5/21 (23.8%) interviews to ensure reliability. Between ER and JH inter-rater agreement was high (92.25%) and inter-rater reliability was good (Cohen's Kappa = .664).

Based on their history with cancer and anxiety/depression, participants were categorised by two authors (ER and JS) into four groups: cancer associated with anxiety/depression AND a history of episodic anxiety/depression or anxiety/depression caused by cancer alone (Group 1; ten participants); cancer associated with anxiety/depression AND long-term anxiety/depression (Group 2; six participants); cancer that was not associated with anxiety/depression AND a history of episodic anxiety/depression (Group 3; one participant); cancer that was not associated with anxiety/depression AND long-term anxiety/depression (Group 4; four participants; see Table 5.1). Following the creation of these groups, codes were collated into potential themes, with themes then reviewed, cross-checked for overlap, defined, and named.

Table 5.1

*Participant Groupings Based on History of Cancer and Anxiety/Depression*

	Episodic anxiety/depression (or caused by cancer alone)	Long-term anxiety/depression
Cancer associated anxiety/depression	Group 1	Group 2
No cancer associated anxiety/depression	Group 3	Group 4

## Results

### Demographics and Illness Characteristics

Twenty-two participants were seen, with 21 (3 males, 18 females) meeting inclusion

criteria for participation (one participant had no formal diagnosis of or treatment for anxiety/depression). Participants were aged between 23 and 75 years ( $M = 50$  years,  $SD = 18$  years) and had a current or previous cancer diagnosis, with four participants experiencing anxiety, five experiencing depression, and 12 participants experiencing both anxiety and depression at some point throughout their lifespan. Table 5.2 contains additional demographics and illness characteristics.

Table 5.2

*Demographics and Illness Characteristics*

Characteristic	Characteristic Sub-Categories	<i>N</i> (%)
Country of Birth	Australia	16 (76.2%)
	New Zealand	1 (4.8%)
	England	3 (14.3%)
	Scotland	1 (4.8%)
Education (highest level obtained)	Year 9 or Below	1 (4.8%)
	Year 10	2 (9.5%)
	Year 12	2 (9.5%)
	Certificate	5 (23.8%)
	Diploma	3 (14.3%)
	Undergraduate Degree	5 (23.8%)
	Post-Graduate Degree	3 (14.3%)
Employment Status	Paid Full-Time Work	2 (9.5%)
	Paid Part-Time Work	2 (9.5%)
	Paid Casual Work	2 (9.5%)
	Retired	6 (28.6%)
	Not Working Due to Health	6 (28.6%)
	Job Seeker	1 (4.8%)
	Other	2 (9.5%)
Relationship Status	Married	10 (47.6%)
	Divorced	1 (4.8%)
	Separated	1 (4.8%)
	De-facto Relationship	4 (19.0%)
	Single	5 (23.8%)

Primary Cancer Type	Breast	9 (42.9%)
	Bowel	5 (23.8%)
	Sarcoma	1 (4.8%)
	Hodgkin's Lymphoma	1 (4.8%)
	Non-Hodgkin's Lymphoma	1 (4.8%)
	Brain	1 (4.8%)
	Liver	1 (4.8%)
	Prostate	1 (4.8%)
	Unknown Primary	1 (4.8%)
Diagnosis of Second Primary Cancer	Yes	3 (14.3%)
	No	18 (85.7%)
Diagnosis of Secondary Cancer	Yes	4 (19.0%)
	No	17 (81.0%)
Cancer Treatment Stage	Peri-Treatment	5 (23.8%)
	Post-Treatment	16 (76.2%)
Cancer Treatment Type	Surgery	20 (95.2%)
	Chemotherapy	16 (76.2%)
	Radiotherapy	12 (57.1%)
	Hormone Therapy	6 (28.6%)
	Tablet Medication	7 (33.3%)
Order of Illness Diagnosis	Cancer pre- Anxiety	2 (12.5%)
	Anxiety pre- Cancer	11 (68.8%)
	Anxiety and Cancer Together	3 (18.8%)
	Cancer pre- Depression	5 (29.4%)
	Depression pre- Cancer	7 (41.2%)
	Depression and Cancer Together	5 (29.4%)
Other Multimorbid Conditions	None	9 (42.9%)
	One	9 (42.9%)
	Two	3 (14.3%)

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## DASS-21

On average, anxiety scores were in the moderate range ( $M = 7.43$ ,  $SD = 8.80$ ), stress scores were in the severe range ( $M = 15.52$ ,  $SD = 8.02$ ), and depression scores were in the extremely severe range ( $M = 14.00$ ,  $SD = 11.33$ ), though scores on each subscale ranged from

normal to extremely severe.

### **Thematic Analysis**

Differences between the four participant groups (see Table 5.1) were identified across two superordinate themes, with each superordinate theme broken into several additional subordinate themes (see Figure 5.1). The first superordinate theme, ‘Coping with Cancer’, describes and compares *coping strategies*, *personal relationships*, and *fear of cancer recurrence (FCR)* across participant groups. The second superordinate theme, ‘Health Care System Support Provision’, describes and compares *hospital care* and *support services* across participant groups.

#### **Coping with Cancer**

In general, participants in Groups 1 and 2 did not cope as well with their cancer as participants in Groups 3 and 4. More specifically, participants in Groups 1 and 2 required more coping strategies and resources to cope with their cancer, while also perceiving and describing less social support and a higher FCR, than participants in Groups 3 and 4.

#### ***Coping strategies.***

Most participants in Groups 1 and 2 received formal psychological treatment for cancer-related anxiety/depression, though participants in Group 2 generally described this treatment in much less detail and/or were less likely to include this as a coping strategy for cancer. Participants in Groups 3 and 4 reported the use of less formal coping and self-management strategies, such as being positive, taking control where possible, keeping busy, and keeping life as normal as possible, with no treatment for cancer-related anxiety and depression described by these participants.

With regard to support groups specifically, eight of ten people in Group 1, and four out of five people in Group 2, attended a support group for cancer-related support. The participants in Groups 3 and 4 did not attend a cancer-related support group. The majority of

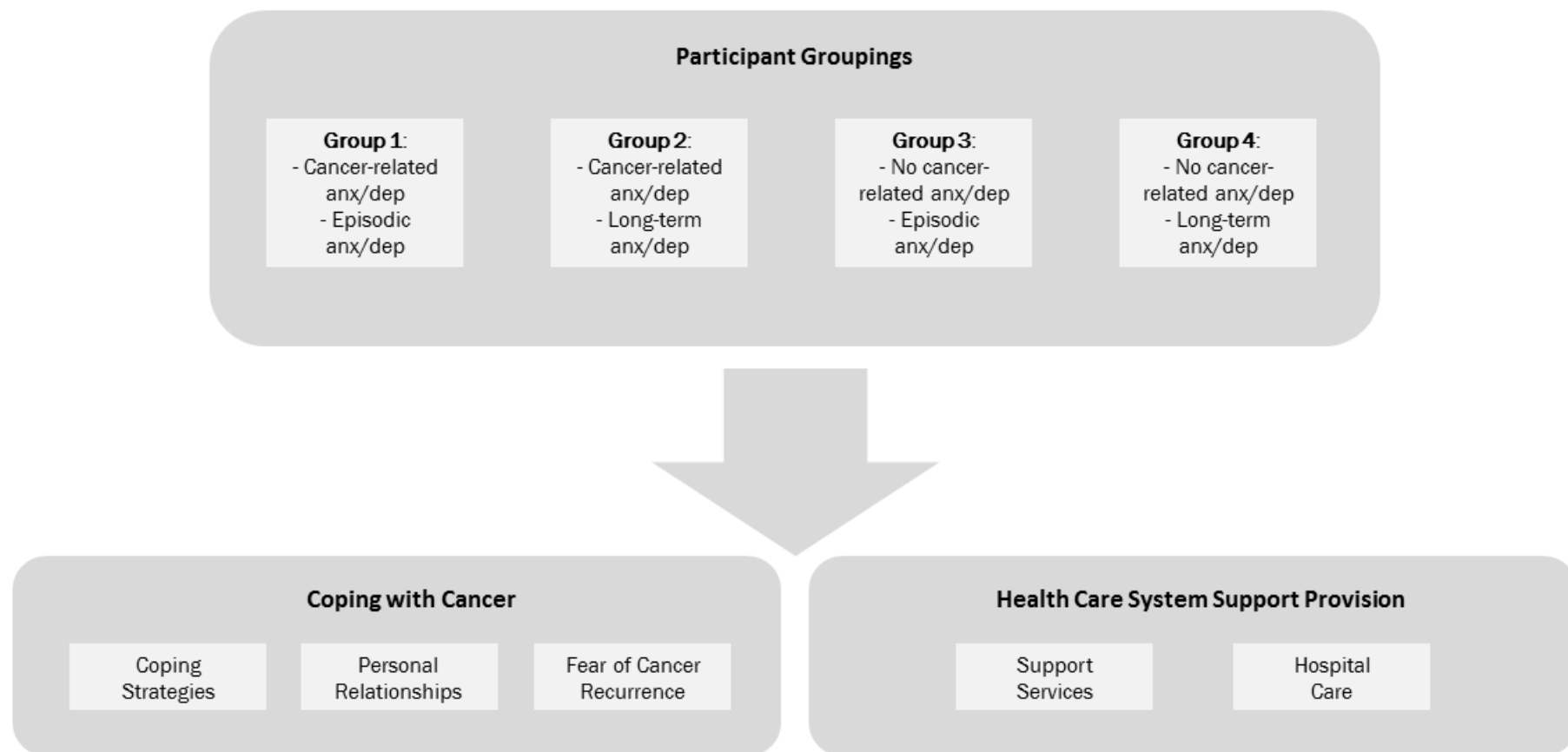


Figure 5.1. Thematic map comparing support needs of people with cancer and anxiety/depression.

participants attending support groups found them highly beneficial.

***Personal relationships.***

For participants in Group 1, strong social support was important, with participants describing how their cancer diagnosis strengthened some relationships but led to the loss of others (most often friendships). Cancer was sometimes described as changing the individual, and therefore changing their relationships. Although some participants in Group 2 described strengthened relationships with their partner or spouse, the majority of these participants described losing friendships and feeling isolated, with less positive social support mentioned overall.

I had a ... friend the other day, a month or two ago I sent her a message and she asked me how I was and I just text her back saying I felt like crap and I was angry and everything, and you know you don't hear from them for a month. So you've got to be careful about what you say otherwise... (ER: Mm.) people just walk away or they just stay away for a, you know, yeah. (Rosalina, Group 2)

In contrast, participants in Groups 3 and 4 described strong social support and personal relationships, with no loss of relationships or support from loved ones described.

***Fear of cancer recurrence (FCR).***

FCR was experienced by participants in Groups 1 and 2, particularly when waiting for test results and when experiencing physiological symptoms that could be a sign of recurrence. However, only participants in Group 1 experienced highly maladaptive FCR post cancer treatment, which was described as occurring once they had time to process what had happened to them.

It wasn't until after, well after 12 months that I really ... started to feel the effects of anxiety and stuff. (ER: Mm.). When the oncologist visits dropped off, when you didn't need to see a surgeon again. ... When chemo finished ... So that's when it started to mess with me. (Freya, Group 1)

If I started to feel an ache or pain somewhere ... I would get that focused on it I'd physically make, make myself ... sick, and I'd, you know, I'd feel worse than I was, you know, I'd have tingly feelings and all sorts of weird feelings that I thought "well I'm going to die" or something... (Eve, Group 1).

Participants in Groups 3 and 4 were much less concerned about FCR, with minor worry occurring when awaiting test results and when thinking about the possibility that they



may miss symptoms of a recurrence.

### **Health Care System Support Provision**

In general, participants in Groups 2 and 4 described experiencing good support from the hospital and appropriate integration with support services, while participants in Group 1 described a lack of support and information from the hospital and a lack of integration with appropriate support services. The participant in Group 3 made no specific comments regarding the hospital system or use of support services.

#### ***Hospital care.***

Participants in Group 1 generally described a lack of support and information from the hospital with regard to mental health and support services (though some participants felt adequately supported). This was particularly highlighted by participants at the post-treatment stage.

It's a business ... getting the cancer sorted out, and getting the cancer over with, as far as the hospital and all that is concerned. (ER: Mm.). So, and it was like, once it stopped it was like "ah, what now?" ... I said to my psychologist today, "It was like... the treatment should only be starting now..." (Sienna, Group 1)

In contrast, participants in Groups 2 and 4 felt that the hospital system was mostly good, with less needs described.

I went Private, and they were brilliant. ... They'd give you this and they'd give you that, and I didn't take any of it, because well why, there was people going to be worse off than me. (Quinn, Group 4)

In general, interviews suggested that those with no prior support or treatment in place for anxiety/depression required more support from the hospital than those with long-term and/or previous mental illness experiences.

#### ***Support services.***

A lack of integration with appropriate support services for people with cancer, a lack of information, and few links with counselling or psychological support services, were described by multiple participants in Group 1. In particular, Doctors (and the hospital system) were often described as failing to link their patients with appropriate support services.

I don't know what it would be like for anybody who, um, doesn't have support. ... cause the Doctor didn't, nobody sort of said "do you want counselling?". ... there was no offer of counselling. ... Even nobody mentioned the Support Group. (Bella, Group 1)

Doctors need to be more responsible, more proactive ... and stop being this sausage factory of putting people through as quickly as you possible. ... And I think a lot of people probably find it more difficult after treatment has finished, because there's nothing. ... And ... the lack of links with people that are integrative medicine specialists, like um homoeopathic, ah naturopaths, physio ... psychologists. There's just no central link to the whole thing. (Bianca, Group 1)

In contrast, participants in Group 2 (bar one) and Group 4 perceived solid links with support services, though some of these participants had links with mental health services already in place prior to their cancer diagnosis.

## Discussion

This qualitative study aimed to compare and examine the existing supports and needs of people with cancer and different histories of depression/anxiety. Our findings suggest that a person's support needs may differ based on their history of coping with anxiety/depression premorbid to their cancer diagnosis. More specifically, we found that participants with anxiety/depression associated with cancer (no matter the origin or history of their anxiety/depression) were much more likely to access formal coping strategies such as psychological treatment for cancer-related anxiety/depression, attend cancer support groups, lose personal relationships because of their cancer, and experience severe maladaptive FCR, than participants with anxiety/depression not associated with cancer (no matter the origin or history of their anxiety/depression). Our results also found that participants with episodic or cancer-related anxiety/depression felt less well supported by the hospital system and experienced less links with support services than participants with long-term anxiety/depression.

Many of the participants in this study had a vulnerability for experiencing anxiety/depression associated with their cancer due to their history of long-term anxiety/depression (Mehta & Roth, 2015). Interestingly, however, only some of these participants experienced cancer related anxiety/depression (Group 2), with these same

participants demonstrating poorer coping, needing more anxiety/depression treatment, and experiencing worse FCR. To better understand why this might have occurred, it is important to consider how and why those with a premorbid history of long-term anxiety/depression and anxiety/depression in response to their cancer (Group 2) might differ from those with a similar history who did not experience any cancer-related anxiety/depression (Group 4). Participants in Group 2 were generally younger than those in Group 4, had an average of one additional chronic illness per person (whereas only one participant in Group 4 had an additional chronic illness), reported they received more misinformation and misdiagnoses from health professionals, described less positive social support interactions, and perceived more, and more severe, cancer related psychosocial consequences. This is in line with previous research that suggests that cancer patients who are younger (Dunn et al., 2013; Hulbert-Williams, Neal, Morrison, Hood, & Wilkinson, 2012; Linden, Vodermaier, Mackenzie, & Greig, 2012), have additional chronic illnesses (J. M. Gunn et al., 2010; Ritchie, Kvale, & Fisch, 2011), less social support (Pinar, Okdem, Buyukgonenc, & Ayhan, 2012; Singer et al., 2012), and more negative illness representations (Richardson et al., 2016), are more likely to experience higher levels of distress. This suggests that together with these potential risk factors, people who also have a history of long-term anxiety/depression and who have not developed coping strategies to manage these issues might be at risk to develop cancer-related anxiety/depression, and therefore may be more at need for support to prevent or decrease such anxiety/depression.

Participants with episodic or cancer-related anxiety/depression (Group 1) often felt less supported by the hospital system and experienced less access to appropriate support and mental health services than participants with long-term anxiety/depression (Groups 2 and 4). Our findings suggest that this was likely due to a lack of prior exposure to mental health and support services, as participants with previous or existing links with such services required

less hospital support and service access. One other potential explanation for this pattern of results lies with the setting for our study, a regional area of Australia (Australian Bureau of Statistics, 2011) with no cancer-specific hospitals, cancer centres, and a lack of individualised services and tailored support (particularly psychological services). Research suggests that people in rural/regional settings often experience worse outcomes, limited access to tailored cancer-specific hospital care, a lack of psychological support, and few links and referrals to other key support services (Butow et al., 2012; K. Gunn, Turnbull, McWha, Davies, & Olver, 2013).

### **Implications**

Our study suggests that a person's history of anxiety/depression may influence how they cope with their cancer experience. In terms of distress trajectories in cancer patients (Dunn et al., 2013; Helgeson et al., 2004; Henselmans, Helgeson, et al., 2010; Lam, Shing, Bonanno, Mancini, & Fielding, 2012), our findings suggest that those who have a history of anxiety/depression that is unrelated to cancer might be better able to cope with the combined burden resulting from both the mental and physical illness than those whose anxiety/depression is cancer related. The knowledge that inexperience in coping with anxiety/depression might place a person at risk of a trajectory of chronic distress post cancer could inform targeted implementation of appropriate resources and services for people at risk. However, more research is needed to determine which facets of a person's anxiety/depression history might be most important in predicting such trajectories. Coping repertoire and skills to manage psychological distress would be particularly worthy of exploration.

In terms of service provision, our study is in line with previous research (K. Gunn et al., 2013; Rainbird, Perkins, Sanson-Fisher, Rolfe, & Anseline, 2009) and suggests a need for patients to receive additional support and information from hospitals, as well as referrals to external mental health and support services where required. However, hospitals often lack the

resources to implement such changes, particularly in rural/regional areas. This study suggests that these limited resources are best directed towards increasing information and links with support services for people with cancer related anxiety/depression, rather than for those who report coping well with a history of long-term anxiety/depression. This is because the latter group often already have existing support systems in place, while people with cancer related anxiety/depression are distressed, have less social support, and experience more severe FCR. For the same reasons it is also suggested that health professionals recommend the use of appropriate support services (including support groups) to people with cancer related anxiety/depression. Our findings highlight the importance of investigating a cancer patient's history of anxiety/depression to determine how much support they may (or may not) require.

### **Limitations**

Although we attempted to differentiate between people with episodic anxiety/depression and people with long-term anxiety/depression, no clinical diagnostic measures or criteria were used to assess this during the interview process. Instead, two researchers (ER and JS – a clinical psychologist) placed participants into groups based on participant data (demographic and interview). Participants were assigned to groups based upon consideration of their reported family history of psychological disorders, psychological responses to past significant life events and premorbid experience of anxiety/depression generally, as well as their reports of their response to their cancer experience.

Due to the widely varied cancer types, cancer stages, and treatment types, experienced by our sample, more consensus could potentially have been found with the use of a more focused sample, such as the inclusion of participants who only have bowel cancer or early-stage disease (Stage 1). Conversely, our more diverse sample may have led to additional insights. As our sample provided both overlapping and unique representations across groups, a good balance between specificity and diversity appears to have been achieved. However, as

only one participant had episodic anxiety/depression that was not related to cancer (Group 3), results from this specific participant category should not be generalised to others in similar situations.

## **Conclusions**

In conclusion, our study has highlighted the need for both researchers and health professionals to give more consideration to the origin and history of a person's anxiety/depression in order to determine how they might cope with cancer, their support needs, and the amount of support required during the diagnosis, treatment, and survivorship phases of cancer.

## **Chapter 6**

### **Discussion**

The aim of the present thesis was to understand how people cognitively represent cancer and anxiety/depression and to examine how these illness representations might influence coping behaviours, self-management strategies, illness outcomes, and support needs using the Common Sense Model of Self-Regulation of Health and Illness (CSM; Leventhal et al., 1980). Four complementary studies were conducted to build an evidence base to meet this aim. Study 1 involved the completion of a systematic review and meta-analysis to synthesise existing literature on the relationships between illness representations, coping behaviours, and illness outcomes in people with cancer. Study 2 consisted of a systematic review and meta-analysis synthesising the findings of the relationships between illness representations, coping behaviours, and illness outcomes in people with depression (a lack of published studies precluded a systematic review on studies in people with anxiety). As a first foray into exploring co-morbid illness representations in people with cancer and anxiety/depression, Study 3 involved the completion of qualitative interviews with people who had this combination of illnesses. These interviews were aimed at examining the content of multimorbid illness representations, as well as analysing how these representations would impact the use and effectiveness of self-management strategies. Finally, Study 4 examined how the subjective support needs of cancer patients/survivors differed between people with varying histories of anxiety/depression (e.g., episodic versus long-term) and how these needs might fit with a person's co-morbid illness representations in order to provide suggestions for how support provision could be improved for this population. The key aims, findings, and conclusions from each of these studies are summarised in Table 6.1. This discussion chapter will integrate the main findings from each of these four studies, highlight both the theoretical and practical implications uncovered by this research, identify areas and considerations for future research, discuss potential limitations, and draw overall conclusions.



Table 6.1

*Summary of the Findings in the Present Thesis*

	<b>Aims</b>	<b>Findings</b>	<b>Conclusions</b>
<b>Study 1 Chapter 2</b>	To provide a systematic overview of the relationships between the Common Sense Model's (CSM) illness representations and health and coping outcomes in people with cancer.	Greater identity, consequences, and emotional representations, a more chronic timeline, as well as less illness coherence, personal and treatment control, was associated with more adaptive coping behaviours (e.g., cognitive reappraisal) and illness outcomes (e.g., psychological distress).	Illness representations are key factors to understanding how individuals respond to cancer, with interventions aimed at changing or reframing maladaptive representations required to improve the coping strategies and illness outcomes of people with cancer.
<b>Study 2 Chapter 3</b>	To provide a systematic overview of the relationships between the CSMs illness representations and health and coping outcomes in people with depression.	More severe consequences were found to be associated with more coping efforts, while greater identity, consequences, and emotional representations, a more chronic timeline, and lower control were associated with increased psychological distress.	This review suggests that illness representations are important for understanding how people respond to depression, with research examining the effectiveness of adjusting key representations in CBT-based interventions required.
<b>Study 3 Chapter 4</b>	To explore the content of individual's multimorbid representations of cancer and anxiety/depression, as well as how these relate to their coping behaviours and self-management strategies.	The majority of participants perceived cancer and anxiety/depression as related, though some perceived them as unrelated or were unsure about their relationship. When described as related, participants using adaptive combination self-management strategies (e.g., meditation) coped better than those who tried to ease cancer related anxiety/depression with strategies that could be considered maladaptive (e.g., internet research).	In order to improve health care interactions and increase the use of adaptive self-management strategies, health professionals need to develop a deeper understanding of patients' multimorbid representations of cancer and anxiety/depression, the effectiveness of combination management for multimorbid illnesses, and the ongoing challenges faced by cancer patients and survivors.
<b>Study 4 Chapter 5</b>	To examine and compare the support needs of people with cancer and varying histories of anxiety/depression in order to provide suggestions for improvements in support and service provision.	Cancer patients with long-term anxiety/depression that was not associated with their cancer diagnosis coped best with cancer and experienced less fear of cancer recurrence. These participants also highlighted more positive experiences with, and required less support from, hospitals and support services.	Both researchers and health professionals should examine a cancer patient's origin and history of anxiety/depression in order to facilitate improvements in coping with cancer, reduce fear of cancer recurrence, and determine the type and amount of support needed by a person living with or post a cancer diagnosis.

## Summary of the Main Findings

### *Illness Representations, Coping Behaviours, and Illness Outcomes in People with Cancer, Anxiety, and/or Depression*

In Study 1, Study 2, and Study 3, the illness representation dimensions were related both to specific coping behaviours and illness outcomes in people with cancer, depression, and cancer and anxiety/depression. Study 1 found that less perceived personal control over cancer, less perceived treatment control over cancer, perceptions of a more chronic or cyclical timeline for cancer, perceptions of more serious consequences of cancer, and a stronger emotional impact of cancer (higher emotional representations), were associated with the use of maladaptive coping strategies such as avoidance/denial. In contrast, perceptions of more personal and treatment control, acute timeline perceptions, less perceived consequences, and less emotional impact of cancer, were associated with the use of more adaptive coping strategies such as cognitive reappraisal and problem focused coping. Study 2 included a limited number of studies investigating the relationships between illness representations and coping behaviours in people with depression. This meant that for the meta-analysis in Study 2, specific coping behaviours were collapsed into one coping scale that measured the extent to which participants used or did not use a coping behaviour, making comparisons with Study 1 difficult. The meta-analysis in Study 2 found that perceptions of more severe depression related consequences and more perceived treatment control were related to the use of more coping strategies (both adaptive and maladaptive). However, similarly to the findings of Study 1, the summary of the studies included in the narrative review suggests that more perceived personal and treatment control were associated with the use of more adaptive coping strategies (e.g., treatment seeking, problem solving, active coping, positive reframing).

With regard to illness outcomes, Study 1 found that more perceived symptoms of

cancer (higher identity), perceptions of a more chronic or cyclical timeline for cancer, perceptions of more severe consequences of cancer, less perceived personal control over cancer, less perceived treatment control over cancer, and more emotional impacts of cancer (higher emotional representations), were associated with worse illness outcomes, including higher anxiety, depression, and psychological distress, as well as poorer psychological well-being, role functioning, physical functioning, and quality of life. The opposite profile of perceptions (lower identity, timeline, consequences, emotional representations, and higher personal and treatment control) was associated with better illness outcomes (less anxiety, depression, and psychological distress, and better role and physical functioning, and quality of life). Study 2 found similar associations to those identified in Study 1, with a stronger emotional impact of depression (higher emotional representations), perceptions of more depression related symptoms (higher identity), perceptions of more severe depression related consequences, perceptions of a more chronic timeline for depression, less perceived personal and treatment control over depression, and less perceived understanding of depression (illness coherence), associated with higher levels of psychological distress. Overall these findings were consistent with the existing literature, in which similar associations between illness representations, coping behaviours, and illness outcomes in people with a variety of chronic physical and mental illnesses were found (Baines & Wittkowski, 2013; Dempster et al., 2015; Hagger & Orbell, 2003)

A final important finding from Study 1 pertains to the high rates of heterogeneity that was identified across several meta-analytic analyses. For example, illness coherence had particularly high heterogeneity, meaning that associations between coherence and outcomes were unable to be identified, most likely due to the presence of a moderator. Several other relationships between illness representations and illness outcomes were found to have high heterogeneity, and although several potential moderators were identified (e.g., cancer type,

cancer stage, treatment type, or treatment toxicity) these were unable to be examined due to missing and unreported information. The systematic review by Hagger and Orbell (2003) also found considerable heterogeneity amongst relationships between illness representations, coping behaviours, and illness outcomes in people with different chronic illnesses. However, similarly to the findings of Study 1, moderator analyses were unable to be examined due to the low number of studies in their sample.

Using the CSM as a framework to explore the illness representations of people with co-morbid cancer and anxiety/depression, Study 3 found both support for the existing illness representation dimensions as applied to single illnesses, as well as for new multimorbid representations of illness. Specifically, more symptoms of cancer (higher identity), more severe consequences of cancer, and less perceived control caused by the cancer, prevented the use of adaptive coping strategies and were associated with more severe anxiety/depression. These findings matched those of Study 1 and Study 2, in which identity, consequences, and control were found to have similar associations with anxiety, depression, psychological distress, and coping strategies (e.g., lower cognitive-reappraisal and problem-focused coping) in people with cancer and in people with depression. However, in Study 3 these findings were extended by the existence of subjective representations about multimorbidity. Study 3 participants were found to think about the relationships between cancer and anxiety/depression in different ways. While some perceived them as unrelated or were unsure about their relationship, the majority of participants perceived their cancer and anxiety/depression as related. These results matched those from a previous study by Mc Sharry et al. (2013) in people with diabetes and depression. In Study 3, when participants described cancer and anxiety/depression as unrelated or were unsure about their relationship, a distant timeline between illness diagnoses, less understanding of anxiety/depression, and the use of separate coping and self-management strategies for each illness were most often

described. Separate self-management strategies for illnesses perceived as unrelated were also generally described by participants in the study by Mc Sharry et al. (2013). When illnesses were considered related these links were often described as being causal (Mc Sharry et al., 2013). For example, some participants believed their cancer caused their anxiety/depression, while others believed their anxiety/depression caused their cancer. It is important to note that generally the consequences of cancer and its treatment were described as causing anxiety/depression, rather than the cancer itself. Both separate and combination coping and self-management strategies were described by people who perceived their cancer and anxiety/depression as related, with participants who used adaptive combination strategies (e.g., meditation) coping better with cancer related anxiety/depression than those who used maladaptive strategies (e.g., unguided internet research).

Study 3 also identified representations on prioritising illnesses, and participants identified the illness they found most challenging (cancer or anxiety/depression), with a more chronic or cyclical timeline, less perceived control, and less understanding (illness coherence), associated with perceptions of a more challenging illness. These findings were supported by Bower et al. (2012), who highlighted the importance of perceived control for illness prioritisation. Which illness a person finds most challenging appears likely to influence which illness they will prioritise in terms of self-management and treatment (Mc Sharry et al., 2013; Schüz et al., 2014). Changing perceptions and needs were also identified across the cancer experience, with different illness representations likely to be present at different stages of the illness timeline. These changing representations were associated with changes in coping and self-management strategies. Study 3 also highlighted how representations related to fear of cancer recurrence (FCR) often lead to the use of maladaptive coping and self-management strategies. For example, those who perceived a cyclical timeline for cancer, more severe consequences of cancer, less perceived control over cancer, and less

understanding (illness coherence) of cancer, were more likely to have high FCR, and to use coping and self-management aimed at reducing this FCR. However, these strategies were often maladaptive (e.g., constantly calling or visiting the doctor), suggesting the need for appropriate intervention in this population. These findings from Study 3 are also related to the findings of Study 1, with a more cyclical timeline, more severe consequences, less perceived control, and less illness coherence, associated with higher levels of anxiety in cancer patients (anxiety is a crucial aspect of FCR; Lee-Jones et al., 1997; Simard et al., 2010), as well as the use of less adaptive coping strategies (e.g., a more cyclical timeline is related to increased avoidance/denial).

Study 4 extended this perspective by examining which illness representations influenced the support needs of people with cancer and varying histories of anxiety/depression. In order to examine these differences, participants were placed into four groups. These groups were created based on whether participants had episodic anxiety/depression or long-term anxiety/depression, and whether or not participants perceived their anxiety/depression to be associated with their cancer. Perceptions of more, and more severe, psychosocial consequences of cancer in people with long-term anxiety/depression, were associated with poorer coping, a need for more anxiety/depression treatment, and worse FCR. Further, participants with episodic or long-term anxiety/depression that did not experience any cancer related anxiety/depression perceived greater control over their illnesses, leading to better coping and outcomes. Finally, participants with long-term anxiety/depression generally perceived more control over their illnesses and had a better perceived understanding of their illnesses (more illness coherence), with these participants requiring less support from the hospital system and support services. In contrast, those participants with episodic or cancer related anxiety/depression often perceived less control over and understanding of their illnesses, with less hospital support, access to external

support services, and access to mental health services described.

In summary, all four studies provide strong evidence for the applicability of the CSM to people with cancer and anxiety/depression, with the CSMs illness representation dimensions found to be particularly important for predicting the health and coping outcomes of the people in this population. The most important predictors of coping behaviours, illness outcomes, and support needs, included timeline, consequences, control, and illness coherence, with support found for each of these dimensions across all four studies. Other illness representation dimensions were found to be important across specific studies only (identity, Studies 1, 2, and 3; cause, Study 3). Finally, while emotional responses (emotional representations) to illnesses (e.g., fear) were found to influence coping and self-management strategies throughout this thesis, associations between emotional representations and illness outcomes were difficult to disentangle in studies that examined anxiety/depression as an illness (rather than an outcome).

#### *Support Needs for People with Cancer and Anxiety/Depression*

Study 3 and Study 4 demonstrate the need for people with cancer and anxiety/depression to receive better support, with these studies able to provide insights into the specific support needs of people with these illnesses. Similarly to previous research, Study 3 found that illness representations and associated support needs change throughout the cancer experience, with different needs identified at different stages of illness timeline (e.g., at diagnosis versus during treatment versus post treatment) (Fischer et al., 2013; McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2010). Because of this, continued support for cancer patients and survivors with anxiety/depression is paramount, with more consideration of these needs at key stages of the cancer experience required by health professionals. Support needs were also found to differ based on which illness participants found more challenging (anxiety/depression or cancer), with more needs associated with the illness they

found more challenging. Further, Study 3, Study 4, and previous research have found that higher levels of FCR have been associated with more support needs from the hospital, external support services, and health professionals (Simard et al., 2013). Both Studies 3 and 4 also found that people with extremely severe cases of FCR often constantly contact health professionals for advice, and can even require hospitalisation. In order to address the needs of people with cancer and anxiety/depression, Study 3 suggested that health professionals should increase their understanding of the illness representations held by people with these illnesses.

Study 4 found differences between the support needs of people with cancer and episodic anxiety/depression and people with cancer and long-term anxiety/depression, as well as between people with anxiety/depression related to (or caused by) their cancer and people with anxiety/depression that was not related to their cancer. More specifically, participants with both episodic and long-term anxiety/depression that was perceived as associated with their cancer coped less well with their cancer, required more psychological treatment for their anxiety/depression, attended more cancer support groups, lost more personal relationships because of their cancer, and experienced worse FCR, than participants with anxiety/depression that was not associated with their cancer. Further, people with episodic cancer related anxiety/depression generally felt less supported by the hospital system and experienced fewer links with appropriate support services than people with long-term anxiety/depression. This suggests that people with episodic cancer related anxiety/depression have a need for increased access to relevant support services. Overall, despite a large body of literature aimed at reducing support needs and improving illness outcomes in people with cancer, it appears that there is still room for improvement in this area (Carey et al., 2012; Galway et al., 2012). More knowledge about the content of illness representations appears likely to deepen our understanding of the needs of people with cancer and anxiety/depression,



as well as to provide insights into how to address such needs.

## **Theoretical Implications and Future Research Directions**

### *Role of the CSM in Cancer and Anxiety/Depression*

The Common Sense Model of Self-Regulation of Health and Illness (CSM; Leventhal et al., 1980) is the most widely used model to examine the cognitive processes underlying coping behaviours, self-management strategies, and illness outcomes in people with chronic illness. All four of the studies in this thesis found relationships between the CSMs illness representation dimensions, coping, and outcomes, and provided support for the CSM as an appropriate framework for examining the content of illness representations. Additionally, these studies support the CSM as a basis for examining how such illness representations relate to coping and outcomes in people with cancer and anxiety/depression. Each of the distinct illness representation dimensions identified by the model and its associated questionnaires (Leventhal et al., 1980; Moss-Morris et al., 2002; Weinman et al., 1996) were supported by the present thesis, though the extent to which each representation was supported varied across and between studies. These representations were also found to be associated with coping behaviours and illness outcomes in people with cancer, people with depression, and people with co-morbid cancer and anxiety/depression. In general, the results of this thesis, as well as the results of previous review studies (e.g., Baines & Wittkowski, 2013; Dempster et al., 2015; Hagger & Orbell, 2003), have found that a more positive profile of representations is associated with the use of more adaptive coping behaviours and better illness outcomes, while a more negative profile of representations is associated with the use of more maladaptive coping behaviours and worse illness outcomes. Although the findings for these relationships were well supported across people with cancer (Study 1) and depression (Study 2) there was a lack of existing research examining these relationships in people with anxiety, with only one study including participants with anxiety located across

the systematic search process included as a part of Study 2 (Hunot et al., 2007). Why this may be the case is not evident, and future research is therefore needed to investigate the relationships between the illness representation dimensions of the CSM, coping behaviours, and illness outcomes in people with anxiety specifically.

The CSMs multi-directional and self-regulative feedback loop suggests that cognitive and emotional responses to an illness guide coping and self-management strategies in parallel, with these strategies later appraised in terms of their success or failure for controlling the illness and its consequences. This appraisal process then leads to the refinement of illness representations, coping behaviours, and self-management strategies, where the feedback loop can start again (Diefenbach & Leventhal, 1996; Hale et al., 2007; Leventhal et al., 1998). Study 3 provided support for this feedback loop, where evidence for changing illness representations, support needs, coping behaviours, and self-management strategies throughout the cancer experience were highlighted. This is in line with research by Mc Sharry et al. (2013), who found that the self-management behaviours associated with illness representations underwent constant appraisal. When coping behaviours were appraised as successful, this positive appraisal was found to reinforce patients' confidence in their multimorbid representations (e.g., that their anxiety/depression was caused by the consequences of their cancer). Further, patients with less clear representations expressed unclear goals for self-management strategies, which in turn resulted in evaluating these strategies as less successful (Mc Sharry et al., 2013). Overall, these findings provide support for the CSMs feedback loop in suggesting that individuals act as problem solvers who constantly appraise and alter their representations and coping behaviours. However, in order to gain a more systematic understanding of specific changes in illness representations and associated coping behaviours over time, as well as how this feedback loop might work for people with multiple illnesses (e.g., co-morbid cancer and anxiety/depression), longitudinal

studies are required (Mc Sharry et al., 2013). These studies should also focus on how the existence of complex multimorbid illness representations and the use of synergistic/antagonistic self-management strategies might influence the functioning of the CSMs feedback loop.

### *Expanding the CSM*

A number of multimorbid illness representations were identified in Study 3, including varied representations of the relationships between (or causes of) cancer and anxiety/depression, beliefs about FCR, perceptions of participants most challenging illness, and changing beliefs across the illness experience. In addition, both Study 3 and Study 4 highlighted the importance of examining a person's history with their illnesses (e.g., which illness came first). The majority of these multimorbid representations were supported by previous qualitative research (Bower et al., 2012; Mc Sharry et al., 2013). Importantly, each of these multimorbid factors and/or representations were shown to influence coping and self-management strategies, with Schüz et al. (2014) suggesting that the way in which people operationalise their illnesses (e.g., combined multimorbid representations versus illness-specific representations) might be dependent on the specific illness outcome under examination (e.g., medication adherence versus physical functioning), though more research is needed to examine such relationships. Although the CSM takes into account some multimorbid factors (e.g., prior illness experience), these findings suggest that the CSM may need to be adjusted or expanded to be more applicable to people with multiple illnesses. In particular, the inclusion of specific multimorbid illness representations including perceptions of the connections, relationships, and causes between illnesses, priorities amongst illnesses, and synergies and antagonisms in the management of illnesses, is recommended, as these were the most commonly identified multimorbid representations across studies (Bower et al., 2012; Mc Sharry et al., 2013).

The development of standardised measures would allow for easier examination and assessment of multimorbid illness representations. Currently, the most widely used measures of illness representations are the illness perception questionnaires (Broadbent et al., 2006; Moss-Morris et al., 2002; Weinman et al., 1996); however these questionnaires need adaptation to be applicable for multiple illnesses. C. J. Gibbons et al. (2013) proposed a new measure of illness perceptions for people with multiple illnesses based on these existing questionnaires and previous qualitative research. Their Multimorbidity Illness Perceptions Scale (MULTIPLEs) consists of five individual subscales including emotional representations, treatment burden, prioritising conditions, causal links, and activity limitations, as well as a summary scale comprising all items from each subscale that measures the overall perceived impact of multimorbidity. Four subscales (emotional representations, prioritising conditions, causal links, and activity limitations) were supported by the results of Study 3, while the prioritisation and causal links scales were also partially supported by the results of Study 4. Neither Study 3 nor Study 4 provided support for the treatment burden scale, with multimorbid medication burden not arising as an important concern in studies of people with cancer and anxiety/depression (Studies 3 and 4). As FCR is a cancer specific consequence, it was not considered for inclusion in the MULTIPLEs. If a specific measure for people with cancer and anxiety/depression was to be created, the inclusion of a subscale that specifically measures FCR, or items measuring FCR as part of an emotional representations subscale, should be considered. Overall, findings suggest that the MULTIPLEs may be appropriate to examine the types of research questions addressed in Study 3, Study 4, and previous research (Bower et al., 2012; Mc Sharry et al., 2013). However, as the MULTIPLEs has not yet been validated for people with co-morbid cancer and anxiety/depression, future research is needed to assess its relevance for answering such questions in this particular population.

Other specific measures of multimorbid illness representations are also beginning to be developed, with Mc Sharry et al. (2015) creating the Diabetes and Depression Representation and Management Questionnaire (DDRMQ). This questionnaire consists of ten subscales including separate representations, negative linked representations, incoherent representations, separate management, linked management integration, linked management struggle, general medication negative effects, general medication burden, diabetes medication worry, and depression medication worry. The majority of these subscales (separate representations, negative linked representations, incoherent representations, separate management, linked management integration, linked management struggle) appear transferrable to people with cancer and anxiety/depression, as they are supported by the findings of Study 3 and Study 4. Study 3 also partially supported each of the medication related subscales (general medication negative effects, general medication burden, and medication worry). However, as this questionnaire was developed specifically for diabetes and depression, cancer specific representations (e.g., FCR representations) were not included. Similarly to the MULTIPLEs, the DDRMQ, if adapted for cancer and anxiety/depression, may be useful for examining the content of illness representations and their relationships with self-management strategies. Nevertheless, the applicability of both the MULTIPLEs and the DDRMQ (altered for people with cancer and anxiety/depression) would need to be investigated in people with cancer and anxiety/depression before either could be used as an appropriate measure of multimorbid illness representations in this population. If neither prove to be appropriate, then a similar more specific questionnaire could be created for people with cancer and anxiety/depression (as has been done with the DDRMQ).

## **Practical Implications and Future Research Directions**

### *Future CSM Interventions*

There is an increasing interest in designing interventions based on the CSM to

improve coping strategies and illness outcomes in people with chronic illnesses. A recent systematic review by Jones, Smith, and Llewellyn (2015) highlights that interventions informed by the CSM have the potential to improve adherence behaviours in people with various chronic illnesses (however, no studies of people with cancer, anxiety, or depression were included). In this review, interventions that had the largest effect on behaviour were those that were delivered by psychologists, involved multiple sessions, included information about antecedents, reattribution, and action planning, and targeted control beliefs (matching the findings from the studies in the present thesis). Illness representation based interventions have also been successful in changing outcomes other than adherence. For example, Keogh et al. (2011) conducted a family-based intervention aimed at changing negative/inaccurate illness representations. They found this intervention improved illness self-management, psychological well-being, diet, exercise, and family support in people with poorly controlled type 2 diabetes. Further, Broadbent et al. (2009) found that if illness representations of people with myocardial infarctions were successfully changed, people gained a better understanding of illness information, had higher intentions to attend rehabilitation classes, less anxiety about returning to work, exercised more, and called their GP less. Based on these findings and on the findings of the current thesis, it is suggested that interventions informed by the CSM have the potential to improve coping and outcomes for people with chronic illnesses. However, such interventions for people with cancer should consider several cancer specific factors that may influence the illness representations in this population. For example, representations that would generally lead to more negative illness outcomes for a person with a chronic illness (e.g., representations of a more chronic timeline and severe consequences) may be realistic for a person with cancer, particularly when at an advanced or metastatic stage. In these cases, it may be better to target emotional responses to cancer (emotional representations) and focus on facilitating the use of more adaptive coping behaviours. Targeting emotional

representations might be particularly important for people with cancer and anxiety/depression, as relieving anxiety/depression might improve a person's ability to cope with cancer. In some cases, it may also be beneficial to target different aspects of certain illness representations. For example, although increasing perceived levels of personal or treatment control over the cancer may not be possible, increasing control over other key factors (e.g., everyday events such as pain management) has been found to improve both physical and psychological outcomes (Sand, Olsson, & Strang, 2009; Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, & Cruzen, 1993).

Support for the use of the CSM as a basis for interventions in cancer patients was provided by Stanton et al. (2013), who synthesised information from 16 randomised psychosocial intervention trials in adults diagnosed with cancer. Their review concluded that altering cancer related illness representations in psychosocial interventions has benefits for cancer patients. Two interventions included in this study specifically attempted to use the CSMs illness representation dimensions to improve illness outcomes (Traeger et al., 2013; S. Ward et al., 2008). A representational intervention to decrease cancer pain (RIDcancerPain) was created and conducted by S. Ward et al. (2008). This study used an approach to patient education that involved assessing a patient's illness representations (based on the CSMs representation dimensions) and providing educational information to reduce any misconceptions described by patients (Arida, Sherwood, Flannery, & Donovan, 2016; Donovan & Ward, 2001; Donovan et al., 2007). The RIDcancerPain was delivered in one face-to-face psychoeducational session lasting between 20 and 60 minutes. Five steps were completed beginning with a representational assessment of current beliefs about cancer pain with respect to identity, cause, timeline, consequences, and cure/control. An exploration of any misconceptions and a discussion of any problems arising from holding these misconceptions was then conducted. Following this, replacement information was provided,

and finally patients were given an opportunity for clarification, and a summary of the session. This intervention program was found to reduce existing barriers (misconceptions associated with specific illness representations) and pain severity in people with metastatic cancer, though several illness outcomes remained unimproved by the intervention (e.g., overall well-being). These findings by S. Ward et al. (2008), along with the findings of the present thesis, suggest that interventions aimed at adjusting inaccurate or maladaptive illness representations are likely to be beneficial for improving outcomes in people with cancer. However, interventions examining which illness representations are most amenable to change, as well as which outcomes might be most improved, are required.

A more recent intervention study in men with prostate cancer by Traeger et al. (2013) examined whether changes in illness representations would mediate intervention-based improvements in emotional well-being. Their cognitive-behavioural stress management (CBSM) intervention involved ten weekly two hour sessions focusing on stress management and health maintenance through training in relaxation, cognitive restructuring, problem-solving, coping skills, interpersonal skills, and enhancing support networks. Illness perceptions were specifically targeted through psychoeducation about prostate cancer, cognitive restructuring of cancer related illness representations, and discussion of cancer related experiences, and were designed to normalise experiences and address self-perceptions in the cancer context. The CBSM intervention was found to change key illness perceptions (perceived treatment efficacy or treatment control and understanding of the cancer experience or illness coherence), which in turn led to improvements in emotional well-being. Traeger et al. (2013) suggested that interventions might be further improved by including more explicit strategies for modifying illness representations, as well as by exploring how such interventions can influence representations that change over time. Study 3 supported these suggestions, further highlighting how representations and needs change across the cancer



experience, with changes in illness representations also associated with changes in coping and self-management strategies. Specific research into how future interventions might be able to address such changes over time is required in order to maximise their effectiveness for improving coping and outcomes.

Research using CSM based interventions has led to some promising improvements in illness outcomes in people with chronic illnesses including cancer. However, interventions that specifically aim to challenge and modify maladaptive or unrealistic illness representations in people with cancer and anxiety/depression have yet to be created and trialled, and therefore the creation and assessment of such interventions is an important area for future research. The studies in this thesis, as well as the findings from research previously highlighted, provide some suggestions for which illness representations would be best to target in future interventions for people with cancer, anxiety, depression, and co-morbid cancer and anxiety/depression. For example, interventions that aim to adapt causal perceptions to be more accurate, timeline perceptions to be less cyclical and chronic, decrease perceptions of the amount and severity of the consequences associated with cancer, increase perceived personal and treatment control over cancer, and decrease the perceived emotional impacts of cancer, may increase the use of adaptive coping strategies, reduce poor illness outcomes such as psychological distress, and improve quality of life. Future interventions based on the CSM for people with cancer and anxiety/depression should also take into account the existence of multimorbid representations, including causal representations (e.g., did one illness cause the other illness), which illness a person prioritises or finds most challenging, beliefs about FCR, and the synergisms/antagonisms associated with self-managing multiple illnesses.

With regard to how such interventions might best target these representations, it is suggested that a combination of psychoeducation from cognitive-behavioural therapy (CBT;

A. T. Beck et al., 1979) and the education based Representational Approach (RA; Donovan & Ward, 2001), might be effective for improving coping and outcomes in people with cancer and anxiety/depression. In CBT-based treatments (A. T. Beck et al., 1979; J. S. Beck, 2011) a client's negative and/or inaccurate thoughts and beliefs are modified in order to change and improve emotional responses and behaviours. Before modifications can be made, the patient must become familiar with such thoughts and how they impact emotions and behaviours, with the CSM providing an evidence based starting point for examining the content of such thoughts. These negative automatic thoughts can then be challenged through psychoeducation, reality-testing, and generating alternatives. For example, consider a person who holds a strong belief that their cancer will return (high FCR), who perceives a low amount of control over their cancer, and who self-diagnoses any minor ache or pain as a sign of a cancer recurrence. For this person, reality-testing these beliefs (e.g., how likely is it that a headache is a sign of your cancer returning), and then providing psychoeducation (e.g., providing information about how rare a recurrence of that type of cancer would be), could change these representations to be more accurate and adaptive. However, although CBT has been found to be effective for changing specific underlying beliefs in anxiety and depression (Hollon et al., 2005), therapeutic interventions have yet to use CBT for targeting illness-based cognitions.

The CSM was used to guide the development of the Representation Approach (RA) to patient education (Arida et al., 2016; Donovan & Ward, 2001; Donovan et al., 2007). This approach involves investigating the patients existing illness beliefs using key dimensions from the CSM: identity, cause, timeline, consequences, and control/cure, and explores any misconceptions, gaps, or confusions described. After discussing the consequences of these representations for behaviours, information that fills gaps in knowledge, clarifies confusions, and replaces misconceptions, is provided. The RA has shown potential for changing illness

representations and improving illness outcomes by challenging and altering maladaptive cognitions in people with cancer, with early interventions using the RA showing promise (e.g., S. Ward et al., 2008).

A combination of CBT and the RA may prove effective for improving coping and outcomes in people with cancer and anxiety/depression, as previous research has demonstrated that relatively brief psychoeducational interventions based on the CSM are useful for identifying and modifying illness representations, and in turn improving coping and outcomes (Petrie & Weinman, 2012). However, any intervention aimed at improving the health and coping outcomes of people with cancer and anxiety/depression must also consider how illness representations change over time, as well as how a person's illness history can influence coping and support needs (highlighted by Studies 3 and 4). For example, people with cancer and long-term anxiety/depression may be less likely to require assistance from the hospital system and other external support services than people with cancer and episodic anxiety/depression. In summary, although psychosocial interventions aimed at changing patients' illness representations have shown promise, more research investigating the types and timing of such interventions, as well as the effectiveness of such interventions in people with cancer and anxiety/depression, are required.

#### *Health Professionals' Understanding of Illness Representations*

It is important that health care providers have a good understanding of a patient's illness and a patient's illness beliefs (Street, Makoul, Arora, & Epstein, 2009). However, the results of Study 3 and Study 4 suggest that patients do not believe this is the case. Therefore, in order to better support people with cancer and anxiety/depression, health professionals need to gain a better understanding of the illness representations experienced by people with these illnesses, and how these representations might be associated with the use of particular coping strategies and with specific illness outcomes. Education for health professionals

regarding the content of such representations (individual and multimorbid), as well as the importance and impact of multimorbidity itself, would be important to improve patient coping and outcomes. For example, Study 3 and Study 4, as well as previous research by Bower et al. (2012) and Mc Sharry et al. (2013), suggest that if health professionals were aware of which illness their patients perceived as most challenging and which illness they would prioritise, they would have a clearer picture of where support is most needed for each patient. Previous research has also highlighted the importance of a shared understanding between health professionals and patients for improving patient outcomes (Street et al., 2009). Further, health professionals should be aware that these illness representations will change over time, and therefore continued assessment would be required. Studies 3 and 4, as well as research by McDowell et al. (2010), suggest that these assessments might be particularly important at key stages of an illness experience, for example when a person with cancer moves from the treatment phase to the survivorship phase. As well as providing a solid footing for interventions with patients, the Representational Approach (Donovan & Ward, 2001) may provide a good basis for improving a health professionals understanding of illness representations. This approach to patient education offers a theoretically based model that can help support health professionals to develop a shared understanding of a person's illness representations with the aim of collaboratively developing personalised plans for self-management behaviours (Arida et al., 2016).

#### *Challenge of Co-Morbid Cancer and Anxiety/Depression for Support Provision*

Because cancer and anxiety/depression often co-occur (Massie et al., 2011; Mystakidou et al., 2005; Roy-Byrne et al., 2008), and because these co-morbid conditions are often associated with worse outcomes for patients (L. F. Brown et al., 2010; Mystakidou et al., 2005; Pasquini & Biondi, 2007), it is important that health professionals ask about a person's past and present mental health when they have been diagnosed with cancer. Study 4

showed that examining a person's history with anxiety/depression may lead to important insights into how they might cope with their cancer diagnosis, and the amount and type of support required. However, research has shown that oncologists in particular often require further training to better recognise patient distress and patients' need for further counselling (Gouveia et al., 2015; Söllner et al., 2001). To improve a health professional's ability to identify patient distress, as well as to improve their knowledge of when a patient needs to be referred to additional support services or counselling, validated screening tools such as the revised Beck Depression Inventory (BDI-II; A. T. Beck, Steer, & Brown, 1996) or the Depression Anxiety Stress Scale (DASS; Lovibond et al., 1995) should be utilised. Further, specific training programs for health professionals that focus on providing appropriate relational and psychological evaluation skills, including taking a detailed history of illnesses as suggested by the findings of Study 4, could be implemented to improve accurate detection of distress. Future research should evaluate the effectiveness of these different procedures in health professionals who care for people with cancer and anxiety/depression.

A further challenge for people with co-morbid cancer and anxiety/depression is self-management, as the symptoms of one condition (or the side-effects of the treatment of one condition) might interfere with the coping or self-management strategies for the other condition. For example, Study 3 found that for a person who uses exercise to help cope with their depression, a cancer diagnosis might limit their ability to exercise and therefore exacerbate their depression. These interactions have also been highlighted by previous research in people with co-morbid diabetes and depression: Mc Sharry et al. (2013) found that although exercising lowered the sugar level of a person with diabetes, their depression made it difficult for them to find the energy for exercise. Health professionals should be mindful of the management difficulties or antagonisms that occur in patients with multiple illnesses so that alternative management strategies can be implemented. As well as being

made aware of the potentially negative impacts of multimorbidity on coping and self-management strategies, health professionals should also be aware of the potential benefits of synergistic combination management strategies, as these are likely to improve patient outcomes across multimorbid illnesses. For example, Study 3 highlighted how one participant found meditation beneficial for reducing her anxiety and improving cancer related consequences, while Bower et al. (2012) described how one participant felt that exercise improved both her mood (depression) and arthritis. However, more formal studies of these synergistic effects are required before specific recommendations can be made.

The survivorship phase (Aziz, 2007) is another important part of the cancer experience, with a need for more support at this time highlighted by the findings of Study 3. This post treatment or remission stage of the cancer experience is often described as being even more difficult than peri treatment, with FCR, anxiety, and depression often worsening at this stage (Baker, Denniston, Smith, & West, 2005; Harrington et al., 2010). The participants in Studies 3 and 4 described a lack of support at this post treatment stage, demonstrating the need for many cancer survivors to find both their own coping strategies, as well as access to appropriate support services and allied health professionals. These findings are in line with previous research, as FCR and uncertainty about the future are often highlighted as unmet needs for cancer patients and survivors (Harrison et al., 2009; McDowell et al., 2010). Although not experiencing FCR, patients with metastatic cancer often describe constant concerns about the progression of their cancer, as well as difficulties with self-management of symptoms, treatment side effects, mental health, and coping with the prospect of death (G. Fan, 2007; Irving & Lloyd-Williams, 2010; Rainbird et al., 2009; Schofield, Carey, & Aranda, 2006). Overall, these findings suggest that the mental health and support needs of cancer patients and survivors need to be better monitored across the entire cancer experience rather than purely at the diagnosis or treatment stage, with more support particularly required

for people with cancer and anxiety/depression post treatment.

### *Provision of Appropriate Support and Information*

Connecting cancer patients and survivors with appropriate support services and allied health professionals is extremely important for the promotion of positive outcomes (K. Gunn et al., 2013; Pascoe, Edelman, & Kidman, 2000). However, the studies in this thesis found a lack of integration between people with cancer and anxiety/depression and appropriate support services and information provision. Specifically, health professionals and hospitals often failed to connect people with cancer and anxiety/depression to appropriate support services at key stages of the cancer experience. This lack of support and information was particularly evident immediately post treatment, when the majority of contact with hospitals and health professionals had ended. Inadequate access to appropriate support services has been found to impair patient outcomes, increase distress, and increase FCR (Pascoe et al., 2000; Wang et al., 2016). Therefore, to improve information provision and support for people at this time in particular, the distribution of a tool-kit or information pack might be beneficial (Jefford & Tattersall, 2002). This pack could include information on common thoughts and emotions post treatment (cognitive and emotional representations guided by the findings of Study 3), what to do when experiencing such thoughts and emotions, and information on where and how to access appropriate support services when required. The findings of Studies 3 and 4 suggest that this type of information pack may be particularly relevant for those people in regional/rural settings where tailored access to psycho-oncological support is limited (Butow et al., 2012; K. Gunn et al., 2013; Underhill et al., 2009).

### **Limitations**

In addition to the limitations that have been discussed in previous chapters, several more general limitations and methodological issues must be considered. These limitations are discussed below.

### *Sample*

Due to the reasonably small number of studies located in Study 1, and the limited participant pool for Studies 3 and 4, each of these studies included participants with varying cancer types (e.g., breast or bowel), stages (e.g., early-stage or metastatic), treatments (e.g., chemotherapy or surgery), treatment severity/toxicity (e.g., targeted cancer therapy or traditional chemotherapy), and treatment stages (e.g., peri-treatment or post-treatment). It is highly likely that each of these factors would impact the illness representations of people with cancer or with cancer and anxiety/depression, as psychological distress (including anxiety and depression) and adaptability to cancer have been shown to vary between cancer types and cancer stages (Admiraal et al., 2013; Linden et al., 2012; Strada & Sourkes, 2010; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001), as well as between treatment types and toxicity of treatment (Admiraal et al., 2013; Hack et al., 2010). For example, Linden et al. (2012) found that people with lung, gynaecological, or haematological cancer reported the highest amount of distress at diagnosis, while cancer patients who received treatment other than surgery (e.g., chemotherapy or radiotherapy) were found by Admiraal et al. (2013) to be at a higher risk for experiencing psychological distress. However, these factors were unable to be examined in Study 1 through the use of moderator analyses due to the provision of insufficient data by studies included in the meta-analyses. These factors were also unable to be examined in Studies 2 and 3 due to the limited participant pool, though the overlapping representations and support needs identified suggests these representations and needs may often be similar across varying cancer types, stages, and treatments. To find out how these factors might influence illness representations, self-management strategies, and support needs, future research should consider comparing people with varying cancer types, stages, or treatments.

A further limitation lies in the setting and location of Study 3 and Study 4. The



majority of Tasmania is considered a regional area (Australian Bureau of Statistics, 2011) and has no cancer-specific hospitals or cancer centres, as well as a lack of individualised support and limited access to psychological services. As people living in such regional and remote areas often have different outcomes, needs, and access to services than those living in major urban or metropolitan areas (Butow et al., 2012; Underhill et al., 2009), it is likely that the results of the present thesis (particularly Studies 3 and 4) will have limited applicability for people living outside of regional areas. Therefore, the results of Study 3 and Study 4 should not be generalised to such populations.

The systematic literature search conducted in Study 2 only found one study that examined the relationships between illness representations, coping behaviours, and illness outcomes in participants with anxiety, demonstrating a dearth of research in this area. However, depression and anxiety often occur concurrently, with substantial overlap between these illnesses identified (T. A. Brown, Campbell, Lehman, Grisham, & Mancill, 2001; Clark & Watson, 1991; Pomerantz & Rose, 2014; Zbozinek et al., 2012). This suggests that similar relationships may exist between illness representations and anxiety as between illness representations and depression. Nonetheless, more studies are needed to confirm whether this is true, and until then caution should be taken when making inferences regarding the relationships between illness representations, coping behaviours, and illness outcomes in people with anxiety.

Studies 3 and 4 focused on people with depression and/or anxiety and an analysis of differences between people who had only anxiety, only depression, or both anxiety and depression was not conducted. This means that important differences may have been missed between such groups. However, as previously identified, anxiety/depression have been shown to have substantial overlap, meaning that the differences between these illnesses may be minimal, though future research would be needed to establish whether this is true. Further,

Study 3 did not make clear differentiations between those with diagnosable depression or anxiety and those with ‘normal’ psychological distress associated with the cancer experience, and while Study 4 did attempt to differentiate between people with episodic anxiety/depression and people with long-term anxiety/depression, no clinical diagnostic criteria or measures were used to assess these factors during the interview process. Instead, people were eligible to participate if they reported a previous diagnosis of, or previous treatment for, anxiety/depression via self-report. Although comparative studies have found self-reports to be relatively consistent with objective illness data (Chaudhry, Jin, & Meltzer, 2005), future research should confirm the presence of multimorbidity using objective measures such as medical records or diagnoses from general practitioners (Fortin et al., 2004).

### *Research Design*

Studies 3 and 4, as well as the majority of studies included in Study 1 and Study 2, were cross-sectional in nature, meaning that judgements regarding causality, predictive relationships between variables, and changes over time were precluded. However, Study 1 did use a moderator analysis to compare whether research design (cross-sectional versus longitudinal) influenced the effect sizes of the relationships between illness representations and coping behaviours and illness representations and illness outcomes. Overall these analyses suggested that relationships between illness representations, coping behaviours, and illness outcomes in people with cancer were mostly stable over time, though slightly smaller in effect. Further, Studies 3 and 4 found that illness representations and self-management strategies were likely to change over time, though this information was provided by self-report and therefore caution should be taken if generalising such results. Future studies should employ longitudinal research designs to determine how illness representations, coping behaviours, and illness outcomes might change over time in people with cancer and

anxiety/depression.

There is currently no known existing research examining the content of specific illness representations or the relationship of these illness representations to coping and self-management strategies in people with co-morbid cancer and anxiety/depression. Furthermore, there is a lack of research examining how the support needs of people with cancer vary based on their history with anxiety/depression. Therefore, qualitative research methods were employed to explore such representations, strategies, and needs. Although the use of qualitative methods have been increasingly accepted for exploratory research (Michell, 2004), at times the use of such methods can be seen as a limitation, particularly when poorly constructed and lacking theoretical and analytical detail (Collingridge & Gantt, 2008). In the present thesis, qualitative methods were deemed appropriate for use in Studies 3 and 4, as exploration of a relatively new area of research was required. Further, the Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong et al., 2007) was used in these studies to ensure the appropriate standards for qualitative research were met. A further limitation of qualitative research is the potential for subjective researcher perceptions to unknowingly influence thematic analysis, though as Studies 3 and 4 were conducted from a subtle realist viewpoint, subjective researcher perceptions were constantly acknowledged throughout the analysis process (Mays & Pope, 2000). Finally, the possibility of self-report or recall bias by the participants in Studies 3 and 4 must also be considered as a potential limitation of those studies. Overall, despite the possible limitations associated with the use of qualitative research, important implications were able to be drawn from these studies, though caution must be taken when generalising such results. Future research should address these limitations by using experimental or questionnaire-based research to confirm the findings from Studies 3 and 4.

## Conclusions

This thesis has demonstrated the importance of understanding subjective illness representations for facilitating better coping behaviours, self-management strategies, illness outcomes, and access to support services in people with cancer and anxiety/depression. Further, the CSM was shown to provide a strong theoretical basis from which to explore such representations. Illness representations including timeline, consequences, personal control, and illness coherence, were found to have important associations with coping behaviours and illness outcomes in people with cancer, anxiety, and depression. Further, multimorbid representations including combined or competing causal representations, beliefs regarding the prioritisation of the illness perceived as most challenging, beliefs about FCR, and perceived synergies and antagonisms in the management of illnesses, were identified as having important associations with self-management strategies and illness outcomes in people with co-morbid cancer and anxiety/depression. These findings highlighted the need for the development of future interventions that aim to adjust incorrect or maladaptive representations in people with cancer and anxiety/depression. Further, the discovery of multimorbid representations suggests the CSM may need to be adjusted or expanded to be more applicable for people with multiple illnesses. Finally, this thesis also highlighted the importance of increasing health professionals' understanding of illness representations and illness history. This will both foster the promotion of suitable self-management strategies and increase referrals to appropriate psycho-oncological support services, helping to improve the health outcomes of people with cancer and anxiety/depression.

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doi:10.1080/07347332.2012.721491

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Zivkovic, M. V., Buljan, M., Blajic, I., & Situm, M. (2008). Psychological status and illness perceptions in patients with melanoma. *Collegium Antropologicum*, 32, 75-78.

Retrieved from <http://www.collantropol.hr/antropo>

Appendix 2.1 has been removed for copyright or proprietary reasons.

It is a published article: Richardson, E. M., Schüz, N., Sanderson, K., Scott, J. L., Schüz, B., 2016. Illness representations, coping, and illness outcomes in people with cancer: a systematic review and meta-analysis, *Psycho-oncology*, 26(6), 724-737

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	25
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	26
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	27-30
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	30
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	N/A
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	31
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	30-32
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	App 2.3
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	30-31, Figure 2.2, App 2.6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	33
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	32-33
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	33, App 2.10
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	33-34
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	34, App 2.9

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	34, App 2.9
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	39, 43
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	31, Figure 2.2, App 2.6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	34-35, App 2.7 2.8
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	35, App 2.10
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	36-39, Tables 2.1-2.4, App 2.11
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	36-39, App 2.12
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	39, 43
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	45-47
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	48-50
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	47-48, 50
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	N/A

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: [www.prisma-statement.org](http://www.prisma-statement.org).

## Appendix 2.3 Database search strategies (original search) (Study 1)

### Scopus Syntax

#### Advanced Search

PUBYEAR > 1995 AND TITLE-ABS-KEY(tumour\* OR cancer\* OR oncolog\* OR carcinoma\* OR maligna\* OR neoplasm\* OR metasta\* OR \*sarcoma\* OR “gestational trophoblastic” OR leukaemia OR lymphoma OR mesothelioma OR myeloma OR myelodysplastic OR \*blastoma OR melanoma OR waldenstrom) AND TITLE-ABS-KEY("illness perception\*" OR "illness representation\*" OR “common sense” OR Leventhal\* OR “self-regulation” OR IPQ\*)

### Web of Science Syntax

#### Basic Search

*((tumour\* OR cancer\* OR oncolog\* OR carcinoma\* OR maligna\* OR neoplasm\* OR metasta\* OR \*sarcoma\* OR “gestational trophoblastic” OR leukaemia OR lymphoma OR mesothelioma OR myeloma OR myelodysplastic OR \*blastoma OR melanoma OR waldenstrom) AND ("illness perception\*" OR "illness representation\*" OR “common sense” OR Leventhal\* OR “self-regulation” OR IPQ\*))*

Timespan 1995 - 2014

### PubMed Syntax

#### Advanced Search

(tumour\*[TIAB] OR cancer\*[TIAB] OR oncolog\*[TIAB] OR carcinoma\*[TIAB] OR maligna\*[TIAB] OR neoplasm\*[TIAB] OR metasta\*[TIAB] OR \*sarcoma\*[TIAB] OR “gestational trophoblastic”[TIAB] OR leukaemia[TIAB] OR lymphoma[TIAB] OR mesothelioma[TIAB] OR myeloma[TIAB] OR myelodysplastic[TIAB] OR \*blastoma[TIAB] OR melanoma[TIAB] OR waldenstrom [TIAB]) AND ("illness perception\*" [TIAB] OR "illness representation\*" [TIAB] OR “common sense” [TIAB] OR Leventhal\* [TIAB] OR “self-regulation” [TIAB] OR IPQ\* [TIAB])

Custom Date Range 1995 - 2014

### PsycINFO Syntax

#### Command Line

AB, TI(tumour\* OR cancer\* OR oncolog\* OR carcinoma\* OR maligna\* OR neoplasm\* OR metasta\* OR \*sarcoma\* OR “gestational trophoblastic” OR leukaemia OR lymphoma OR mesothelioma OR myeloma OR myelodysplastic OR \*blastoma OR melanoma OR waldenstrom) AND AB, TI("illness perception\*" OR "illness representation\*" OR “common sense” OR Leventhal\* OR “self-regulation” OR IPQ\*)

Enter a specific date range starting 1995 ending 2014

## Google Scholar Syntax

With the exact phrase:

Illness Representation

Illness Perception

Self-Regulation

IPQ

Illness Representations

Illness Perceptions

Common Sense

With at least one of the words: cancer tumour oncology carcinoma malignant malignancy  
neoplasm metastatic metastasis sarcoma leukaemia lymphoma

In the title of the article

Return articles dated between 1995 – 2014

## CINAHL (follow-up search) Syntax

((tumour\* OR cancer\* OR oncolog\* OR carcinoma\* OR maligna\* OR neoplasm\* OR  
metasta\* OR \*sarcoma\* OR “gestational trophoblastic” OR leukaemia OR lymphoma OR  
mesothelioma OR myeloma OR myelodysplastic OR \*blastoma OR melanoma OR  
waldenstrom) AND ("illness perception\*" OR "illness representation\*" OR “common sense”  
OR Leventhal\* OR “self-regulation” OR IPQ\*))

Published date: 1995 - 2015



## Appendix 2.4 Coding manual (Study 1)

# Coding Manual

## 1 General Information

ID No. _____	Cancer Type _____ DV _____
--------------	----------------------------

An article identification number should be included at the top left of each page under **ID No.**, and again in the General Publication Information section of the coding sheet. The 7-digit ID is specified in BLOCK CAPITALS. It is composed of:

- the first three letters of the surname of the first author
- the last two digits of the publication year
- the first two letters of the surname of the second author (if no secondary author: xx)

If several **cancer types** are examined in a publication, a private coding sheet is filled out for each type of cancer. The cancer types in an article are numbered. This number is entered in the upper right corner of each page under **Cancer Type**, and again in the Cancer and Sample Information section of the coding sheet. If the publication examines only one cancer type, the number of the cancer type followed by the word “only” is entered here. **Cancer Type** has been adopted from the American Cancer Society and should be coded as per the categories below:

1 = Adrenal	37 = Hodgkin Lymphoma (Hodgkin Disease)
2 = Anal	38 = Non-Hodgkin Lymphoma
3 = Bile Duct	39 = Lymphoma of the Skin
4 = Bladder	40 = Malignant Mesothelioma
5 = Bone	41 = Multiple Myeloma
6 = Brain / Spinal Cord (Central Nervous System) Tumour	42 = Myelodysplastic Syndrome (MDS)
7 = Breast	43 = Nasal Cavity and Paranasal Sinus
8 = Breast in Men	44 = Neuroblastoma
9 = Cancer of Unknown Primary Source	45 = Oral Cavity and Oropharyngeal
10 = Cervical	46 = Osteosarcoma
11 = Colon / Rectum (Colorectal or Bowel)	47 = Ovarian
12 = Endometrial	48 = Pancreatic
13 = Esophagus/ Esophageal	49 = Penile
14 = Ewing Family of Tumours	50 = Pituitary Carcinomas or Tumours
15 = Eye	51 = Prostate
16 = Head and Neck	52 = Renal Cell Carcinoma
17 = Gallbladder	53 = Retinoblastoma
18 = Gastric	54 = Rhabdomyosarcoma (RMS)
19 = Gastrointestinal Carcinoid Tumours	55 = Salivary Gland
20 = Gastrointestinal Stromal Tumour (GIST)	56 = Sarcoma (Soft Tissue Sarcoma)
21 = Gestational Trophoblastic Disease	57 = Skin Cancer
22 = Kaposi Sarcoma	58 = Basal and Squamous Cell Skin Cancers
23 = Kidney Cancer	59 = Melanoma Skin Cancer
24 = Laryngeal and Hypopharyngeal	60 = Small Intestine
25 = Leukemia	61 = Stomach
26 = Acute Lymphocytic Leukemia (ALL)	62 = Testicular
27 = Acute Myeloid Leukemia (AML)	63 = Thymus

28 = Chronic Lymphocytic Leukemia (CLL)	64 = Thyroid
29 = Chronic Myeloid Leukemia (CML)	65 = Urethral
30 = Chronic Myelomonocytic Leukemia (CMML)	66 = Uterine Sarcoma
31 = Liver	67 = Vaginal
32 = Lung	68 = Vulvar
33 = Non-Small Cell Lung Cancer (NSCLC)	69 = Waldenstrom Macroglobulinemia (WM)
34 = Small Cell Lung Cancer (SCLC)	70 = Wilms Tumour
35 = Lung Carcinoid Tumour	71 = Cancer Type Not Specified
36 = Lymphoma	99 = Other Cancer Type (Specify)

*Note:* Please code cancer type with the most specific cancer type code possible.

If in the publication several **dependent variables** (including separate subscales) are analysed (e.g. psychological distress, and avoidance/denial), each dependent variable is given a number in terms of its DV (Subscale) Type. This number is entered in the upper right corner of each page under **DV**, and again in the dependent variable section of the coding sheet. These numbers are the same for all cancer types. DV (Subscale) Type has been adopted from Hagger and Orbell (2003) and should be coded as per the categories below:

<b>Coping Behaviours</b>	<b>Illness Outcomes</b>
1. Expressing Emotion	11. Affect (Negative/Positive)
2. Cognitive Reappraisal	12. Anxiety
3. Avoidance/Denial	13. Depression
4. Problem-Focused Coping (Generic)	14. Psychological Distress
5. Problem-Focused Coping (Specific - Other)	15. Treatment Related Distress
6. Treatment Decision Making	16. Decisional Uncertainty / Regret
7. Medication Adherence	17. Psychological Well-Being
8. Adherence to Treatment Visits	18. Vitality
9. Doctors Visits	19. Role Functioning
10. Seeking Social Support	20. Physical Functioning
98. Other Coping Behaviour (Specify)	21. Disease State
	22. Quality of Life
	99. Other Illness Outcome (Specify)

### Redundant Information

If multiple coding sheets are filled in for one article, the details that apply to the entire article should be recorded in only one coding sheet, and the corresponding check box (to the right of the questions) should be ticked in other relevant coding sheets.

Therefore a ticked box means that the missing information may be taken from another coding sheet.

### Missing Information

There are two types of missing information:

- Not Applicable: is crossed out in coding sheet and later encoded in data entry with 777.
- Missing: is left open (and possibly supplemented, if one has written to the author).

### Decimal Places

All sample values should be a maximum of two decimal places (rounded).

All statistical values should be a maximum of three decimal places.

### Exclusion Criteria

If one of the following criteria apply, the study must be excluded:

- Study did not use a Quantitative Design: The study used one or more invalidated or unstandardised key measure of interest.
- Study did not use the IPQ or IPQ-R: The study did not measure Illness Representations from the CSM using the Illness Perception Questionnaire or the Revised Illness Perception Questionnaire.
- Study did not measure Coping Behaviours or Illness Outcomes
- Study contained Participants without a Cancer Diagnosis
- Study used (only) Children or Adolescents: Participants must not be under the age of eighteen.
- Study in a language other than English or German: *Note*: We will consider studies in other languages if they include clear results.
- Study was conducted prior to 1995: The study was conducted prior to the creation of the IPQ.

A coding sheet must be created for any excluded study. However, it is sufficient to only fill in the general information for publication section. In addition, the “Study will be Excluded” box should be ticked and reasons should be provided in the comments box on the last page.

## 2 Comments on the Study

☐ Study will be Excluded☐ Write to Authors☐ Important Comments

If problems occurred during encoding, the relevant box should be ticked (with details to be included in the Final Details box on the last page of the coding sheet).

- Study will be Excluded: Reason for exclusion in the final data set.
- Write to Authors: If the publication is lacking important statistical information (e.g. information about the sample size or standard deviations), the coder will try to check this information with the authors. The missing details are mentioned in the Final Details box.
- Important Comments: If any problems/comments are entered in the Final Details box, this field should be ticked – unless these are reasons for exclusion or information about a lack of statistical information.

### 3 General Publication Information

Article Identification Number (ID-No.): \_ \_ \_ \_ \_

Study in Article: \_\_\_\_\_

The Article Identification Number should be the same 7-digit ID (specified in BLOCK CAPITALS) as appears at the top left hand corner of each page. It is composed of

- the first three letters of the surname of the first author
- the last two digits of the publication year
- the first two letters of the surname of the second author (if no secondary author: xx)

If the publication contains several studies that refer to different samples, these studies are numbered. For each study, a separate coding sheet should be created. The respective number of the study is then given here.

Coder: \_\_\_\_\_

Coding Date \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Time of Day: \_\_\_\_\_

Coder: Enter initials of Coder

Coding Date: Day / Month / Year

Time of Day: Specify at the start of encoding in order to determine the total duration of coding

Authors: \_\_\_\_\_

Publication Year: \_\_\_\_\_

Specify the last name of the first three authors. If more than three authors are mentioned, all the other authors are abbreviated with **et al.** The publication year is four digits.

Title (first six words): \_\_\_\_\_

Note the first six words from the title of the publication.

Country of Origin - Author: \_\_\_\_\_

Other Origin: \_\_\_\_\_

The Country of Origin of the first author is usually noted on the publication. If not, it should be googled and entered using the codes below. If the author has more than one Country of Origin, enter this under Other Origin.

### Coding of Country of Origin

- 1 = USA
- 2 = Canada
- 3 = Germany
- 4 = Great Britain
- 5 = Netherlands
- 6 = Scandinavia
- 7 = Australia
- 8 = Western Europe (excluding G, GB, N, Scandinavia)
- 9 = Eastern Europe (including Russia)
- 99 = Other (Specify)

Discipline of the First Author: _____ Other Discipline: _____
---

The discipline of the first author is usually noted on the publication. If not, it should be googled and entered using the codes below. If the author has more than one discipline listed, enter this under Other Discipline.

### Coding of Discipline

- 1 = Psychology
- 2 = Psychiatry
- 3 = Medicine
- 4 = Sociology
- 5 = Economy
- 6 = Education
- 99 = Other

Publication Found In: _____ Other Place Publication Found: _____
--

### Coding where the Publication was Found

- 1 = Scopus
- 2 = Web of Science
- 3 = PubMed
- 4 = PsycINFO
- 5 = Google Scholar
- 6 = Manual Search in Journals
- 7 = Hand-Searches Reference Lists
- 8 = Contact with Researchers
- 99 = Other Source

*Note:* Some publications may be found (or exist) in more than one location or database. The code given will reflect the first place the coders have found the publication.

Type of Publication: _____ Other Publication: _____ Citations: _____ Impact: _____
--

### Coding the Type of Publication

- 1 = Journal with Peer Review
- 2 = Journal without Peer Review
- 3 = Book / Book Chapters
- 4 = Dissertation (PhD)
- 5 = Honours Thesis or Master's Thesis (or German Diploma)
- 6 = Conference Presentation / Poster (Abstract or Full Paper)
- 7 = Unpublished Manuscript
- 8 = Internet Document
- 99 = Other

### Citations

How many citations does the study have (in Scopus)?

### Impact

What is the Impact Factor of the Journal (in Journal Citation Reports)?

## 4 Description of the Study

Study Type: _____	IPQ or IPQ-R Dimension: _____
Reliability Source: _____	Coefficients Type: _____
Number of Items: _____	
Study: _____	

### Coding of Study Type

- 1 = Cross-Sectional
- 2 = Longitudinal
- 3 = Experimental
- 4 = Pseudo-Experimental
- 99 = Other Study Type

### Coding of IPQ or IPQ-R Dimension

- 1 = Identity
- 2 = Cause (Generic)
- 3 = Timeline (Acute/Chronic)
- 4 = Consequences
- 5 = Personal Control
- 6 = Treatment Control Items
- 7 = Illness Coherence Items
- 8 = Timeline Cyclical
- 9 = Emotional Representations
- 10 = IPQ Only – Cure-Control
- 11 = All Dimensions of IPQ
- 12 = All Dimensions of IPQ-R

### Coding of Reliability Source

- 0 = No Information
- 1 = No Information, but reference to another publication (specify study)
- 2 = Yes, calculated using the sample from this publication (specify values)
- 3 = Yes, calculated using a different sample (values and specify study)

If reliability coefficients are given for individual subscales, these should be included later in the coding sheet (in the Statistical Analyses and Effect Sizes section).

If coefficients are drawn from both this sample (coding 2) and from other studies (coding 3) in the publication, only the coefficients of the concrete sample are to be coded.

If there is no information about reliability, but there is a reference in the description of the instrument, this corresponds to Coding 1.

### Coding of Coefficient Type

- 1 = Internal Consistency, E.g. Cronbach's  $\alpha$
- 2 = Split- Halves Reliability
- 3 = Test-Retest Reliability
- 4 = Parallel Test Reliability
- 5 = Mean Value of Several Coefficients
- 6 = No Precise Indication
- 99 = Other Coefficient

### Study

If a reliability coefficient is (or is not) stated, and reference is made to another study, the first three authors and the year of publication of the study are stated under "Study".



### Number of Items

If all dimensions of the IPQ or IPQ-R were measured, provide the number of items for the entire measure here. The number of items for each individual subscale should be included later in the coding sheet (in the Statistical Analyses and Effect Sizes section).

If Experimental:

Number of Groups: \_\_\_\_\_

Group a: \_\_\_\_\_

Group c: \_\_\_\_\_

Assignment: \_\_\_\_\_

Group b: \_\_\_\_\_

Group d: \_\_\_\_\_

The values of various groups are often reported, e.g. for women and for men. In this case, the statistics for each group are reported on a single coding sheet.

*Note:* Only fill out this section of the coding sheet if the study is experimental.

### Number of Groups

Specify the number of groups for which statistics are available. If only one group is available, use a 1. Further, all other fields must not be filled in, but instead crossed out and encoded with 777 (not applicable).

### Assignment

Group allocation:

1 = Randomisation: The subjects were randomly assigned to the groups.

2 = Matched Groups: Each person of one group matches a person of the other group. Each pair has similar properties (e.g. the same age or the same sex).

3 = Natural Groups, parallelised: E.g., women's and men's groups are natural groups. These two groups can also be parallelised for other characteristics (e.g. by having the same mean age).

4 = Natural Groups without further assignment: E.g., comparison of women and men, without other sampling features.

### Group a, Group b, etc.

Each group is assigned a continuous index a, b, c, etc. Note which identify groups, e.g. group a = men, group b = women, or group a = pre-treatment, group b = peri-treatment, group c = post-treatment.

If more than four groups were analysed, the other group affiliations are simply noted on the margin or on a separate piece of paper.

Number of Measurement Points: \_\_\_\_\_

Year of the First Data Collection: \_\_\_\_\_

Number of Measurement Points: Enter a number or **99**, when the number of measurement times varied within the sample. These are only included when statistical information is available for the measurement point.

Year of the First Data Collection: Enter the four-digit year number. If given several years for the first MP, the earliest year is coded.

Lag Between Assessments _____:	MP 5 _____
MP 2 _____	MP 6 _____
MP 3 _____	MP 7 _____
MP 4 _____	MP 8 _____

This box can only be filled in if the distance between the MPs is the same for all individuals, and if statistics are available. The time interval is specified *in months* (rounded if necessary).

Use this scale for the conversion of years, weeks and days into months:

1 Day = 0.03 Months

1 Week = 0.25 Months

1 Year = 12 Months

## 5 Cancer and Sample Information

The information on the sample should refer to the smallest unit of analysis (e.g., males and females separately). If there are several groups, information on the sample for each group should be recorded separately. If this is not possible and only information on the total sample can be accessed, it is sufficient to fill in the Cancer and Sample Information box on a single coding sheet and to tick the box on the right – meaning that this data is applicable across all groups.

Sometimes statistics are only available at the group level, and other times only for the entire sample. In this case, you can mark information as generally applicable by placing a tick in the smaller box to the right of each row. A ticked box means that this information refers to the whole sample. If this box is not ticked, it means that this information refers to the specific group.

Type of Sample: \_\_\_\_\_

The nature of the sample may change during a longitudinal study. For example, students might participate, and after a passage of time, leave the university. It is therefore crucial for to identify what the type of sample was at the first MP.

### Coding the Type of Sample

- 1 = Representative Sample
- 2 = Non-representative Sample of the general population (specify if the study has a name)
- 3 = Students
- 4 = Clinical Sample (E.g. those assessed in a hospital)
- 5 = Cancer Groups, Societies, and Communities (E.g. self-help groups, internet communities)
- 99 = Other type of Sample (specify)

Cancer Type: \_\_\_\_\_

Cancer Stage: \_\_\_\_\_ ☐

### Coding of Cancer Type

**Cancer Type** has been adopted from the American Cancer Society and should be coded as per the categories below:

- |   |   |
|---|---|
| 1 = Adrenal   | 37 = Hodgkin Lymphoma (Hodgkin Disease) |
| 2 = Anal  | 38 = Non-Hodgkin Lymphoma               |
| 3 = Bile Duct   | 39 = Lymphoma of the Skin               |
| 4 = Bladder   | 40 = Malignant Mesothelioma             |
| 5 = Bone  | 41 = Multiple Myeloma                   |
| 6 = Brain / Spinal Cord (Central Nervous System) Tumour | 42 = Myelodysplastic Syndrome (MDS)     |
| 7 = Breast  | 43 = Nasal Cavity and Paranasal Sinus   |
| 8 = Breast in Men                                       | 44 = Neuroblastoma                      |
| 9 = Cancer of Unknown Primary Source                    | 45 = Oral Cavity and Oropharyngeal      |
| 10 = Cervical   | 46 = Osteosarcoma                       |
| 11 = Colon / Rectum (Colorectal or Bowel)               | 47 = Ovarian                            |
| 12 = Endometrial  | 48 = Pancreatic                         |

13 = Esophagus/ Esophageal	49 = Penile
14 = Ewing Family of Tumours	50 = Pituitary Carcinomas or Tumours
15 = Eye	51 = Prostate
16 = Head and Neck	52 = Renal Cell Carcinoma
17 = Gallbladder	53 = Retinoblastoma
18 = Gastric	54 = Rhabdomyosarcoma (RMS)
19 = Gastrointestinal Carcinoid Tumours	55 = Salivary Gland
20 = Gastrointestinal Stromal Tumour (GIST)	56 = Sarcoma (Soft Tissue Sarcoma)
21 = Gestational Trophoblastic Disease	57 = Skin Cancer
22 = Kaposi Sarcoma	58 = Basal and Squamous Cell Skin Cancers
23 = Kidney Cancer	59 = Melanoma Skin Cancer
24 = Laryngeal and Hyphopharyngeal	60 = Small Intestine
25 = Leukemia	61 = Stomach
26 = Acute Lymphocytic Leukemia (ALL)	62 = Testicular
27 = Acute Myeloid Leukemia (AML)	63 = Thymus
28 = Chronic Lymphocytic Leukemia (CLL)	64 = Thyroid
29 = Chronic Myeloid Leukemia (CML)	65 = Urethral
30 = Chronic Myelomonocytic Leukemia (CMML)	66 = Uterine Sarcoma
31 = Liver	67 = Vaginal
32 = Lung	68 = Vulvar
33 = Non-Small Cell Lung Cancer (NSCLC)	69 = Waldenstrom Macroglobulinemia (WM)
34 = Small Cell Lung Cancer (SCLC)	70 = Wilms Tumour
35 = Lung Carcinoid Tumour	71 = Cancer Type Not Specified
36 = Lymphoma	99 = Other Cancer Type (Specify)

*Note:* Please code cancer type with the most specific cancer type code possible.

### Coding of Cancer Stage

The Tumour-Node-Metastasis (TNM) Classification of Malignant Tumours will be used to code cancer stage.

In the TNM system, T refers to the size or direct extent of the primary tumour. Higher numbers indicate increased size, extent, or degree of penetration. Each Cancer Type has specific indicators for classification of a number. N describes whether or not the cancer has spread into nearby Lymph Nodes. Higher numbers indicate greater Lymph Node involvement. M informs whether or not distant metastases have been identified (spread of cancer to other parts of the body).

1 = TX – Primary Tumour cannot be evaluated
2 = T0 – No evidence of Primary Tumour (it cannot be found)
3 = Tis – Carcinoma in situ (early cancer with no invasion of Tumour cells into surrounding tissue)
4 = T1 – Presence of Tumours
5 = T2 - Presence of Tumours
6 = T3 - Presence of Tumours
7 = T4 - Presence of Tumours
8 = NX – Lymph Nodes cannot be evaluated
9 = N0 – No regional Lymph Node Metastasis (Tumour cells are absent)
10 = N1 – Regional Lymph Node Metastasis present
11 = N2 - Regional Lymph Node Metastasis present
12 = N3 – Regional Lymph Node Metastasis
13 = MX – Distant Metastasis cannot be evaluated
14 = M0 – No distant Metastasis (no distant Cancer spread)
15 = M1 – Distant Metastasis (Cancer has spread to distant organs or tissues)
99 = Other Cancer Stage (some cancers are not classified using TNM, e.g. early grade brain tumours – specify the correct stage and include relevant details)

Cancer Duration: M = \_\_\_\_\_ SD = \_\_\_\_\_ Range from \_\_\_\_\_ to \_\_\_\_\_ ☐

Cancer Duration: Record information here regarding the length of time participants have suffered from (been diagnosed with) cancer (in months).

Use this scale for the conversion of years, weeks and days into months:

1 Day = 0.03 Months

1 Week = 0.25 Months

1 Year = 12 Months

M: Mean value.

SD: Standard deviation.

Range: Specify a minimum and maximum Cancer Duration.

Age at Onset: M = \_\_\_\_\_ SD = \_\_\_\_\_ Range from \_\_\_\_\_ to \_\_\_\_\_ ☐

Age at Onset: Record information here regarding which age participants were diagnosed with cancer (in months).

M: Mean value.

SD: Standard deviation.

Range: Specify a minimum and maximum Age at Onset.

Treatment Type: \_\_\_\_\_ Treatment Stage: \_\_\_\_\_ ☐

#### Coding of Treatment Type

- 1 = Surgery
- 2 = Radiotherapy
- 3 = Chemotherapy
- 4 = Hormone Therapy
- 99 = Other Treatment (Specify)

#### Coding of Treatment Stage

- 1 = Pre-Treatment
- 2 = Peri-Treatment (Currently Undergoing Treatment)
- 3 = Post-Treatment

Size of the Sample at each Measurement Point:

MP 1 \_\_\_\_\_

MP 5 \_\_\_\_\_

MP 2 \_\_\_\_\_

MP 6 \_\_\_\_\_

MP 3 \_\_\_\_\_

MP 7 \_\_\_\_\_

MP 4 \_\_\_\_\_

MP 8 \_\_\_\_\_

Here the sample size at each measurement time point is indicated. Sample size includes all participants, regardless of whether or not they were later excluded from the analysis. The point is to show how the sample has changed over time (i.e. mostly reduced).

If multiple groups are examined separately, only the respective group size is specified.

Total N: _____	Retention Rate: _____ %	<input type="checkbox"/>
----------------	-------------------------	--------------------------

Total N: The number of individuals that participated at all time points.

Retention Rate: How high is the percentage of those who have participated in all MPs (total N), compared to the sample for the first MP (can be calculated from the ratio of MP 1 and total N).

Proportion of Men at MP 1: _____ %	<input type="checkbox"/>
------------------------------------	--------------------------

Proportion of Men: Always indicate the MP for which the proportion of men refers.

Age at MP 1 _____: M = _____ SD = _____ Range from _____ to _____	<input type="checkbox"/>
---	--------------------------

Age at MP 1: Specify to whom the information relates. If data is available for several MPs, the information for MP 1 is reported.

M: Mean value.

SD: Standard deviation.

Range: Specify a minimum and maximum age.

Ethnicity: ____ Other Ethnicity: ____ Country of Origin: ____ Other Country of Origin: ____	<input type="checkbox"/>
---	--------------------------

#### Coding of Ethnicity

Ethnicity is specified only if the proportion of this ethnic group makes up a minimum of 50% of the sample.

- 1 = White (Caucasian, Anglo-American, European)
- 2 = Black
- 3 = Hispanic
- 4 = Indigenous People
- 5 = Asian
- 6 = Mixed (when two ethnic groups are represented with 50% each)
- 99 = Other (specify)

Coding of Country of Origin

Specify in which Country the study was conducted.

- 1 = USA
- 2 = Canada
- 3 = Germany
- 4 = Great Britain
- 5 = Netherlands
- 6 = Scandinavia
- 7 = Australia
- 8 = Western Europe (excluding G, GB, N, Scandinavia)
- 9 = Eastern Europe (including Russia)
- 99 = Other (Specify)

## 6 Dependent Variable

No. \_\_\_\_\_ Did the Study aim to change the Dependent Variable? \_\_\_\_\_

### Number of Dependent Variables

If there are several DVs (including separate subscales), the DVs are numbered in terms of their DV (Subscale) Type and a separate coding sheet for each DV is created. This number should also be entered in the top right hand corner of every page. *Note.* As each subscale can be a DV of its own, the number of DVs should include subscales (if their details are to be recorded separately throughout the coding sheet). At “No.” the number of DVs is given.

If only one DV is encoded, this field is crossed out and later coded with 777 (not applicable).

### Did the Study aim to change the Dependent Variable/s?

Did the study aim to change the DV:

0 = No

1 = Yes

DV Global: \_\_\_\_\_ DV Name: \_\_\_\_\_

There are three aspects of the DV that need to be coded. In DV Global, the global category is entered. These are distinguished as:

1 = Coping Behaviour

2 = Illness Outcome

99 = Other (Please Specify)

DV Name indicates the name of the DV which is used in the publication.

Subscale: \_\_\_\_\_ DV (Subscale) Type: \_\_\_\_\_

### Subscale

If only one subscale of an instrument is used, or if data is provided separately for several subscales, this is noted here (by recording the name of the subscale). All other information (e.g., reliability and number of items) will always refer to this subscale, and not the entire instrument.

DV (Subscale) Type has been adopted from Hagger and Orbell (2003) and should be coded as per the categories below:



<b>Coping Behaviours</b>	<b>Illness Outcomes</b>
1. Expressing Emotion	11. Affect (Negative/Positive)
2. Cognitive Reappraisal	12. Anxiety
3. Avoidance/Denial	13. Depression
4. Problem-Focused Coping (Generic)	14. Psychological Distress
5. Problem-Focused Coping (Specific - Other)	15. Treatment Related Distress
6. Treatment Decision Making	16. Decisional Uncertainty / Regret
7. Medication Adherence	17. Psychological Well-Being
8. Adherence to Treatment Visits	18. Vitality
9. Doctors Visits	19. Role Functioning
10. Seeking Social Support	20. Physical Functioning
98. Other Coping Behaviour (Specify)	21. Disease State
	22. Quality of Life
	99. Other Illness Outcome (Specify)

Data Source: \_\_\_\_\_ Additional Information: \_\_\_\_\_

### Coding of the Data Source

- 1 = Self-report Questionnaire
- 2 = Self-report Interview
- 3 = Self-report on Ambulatory Assessment
- 5 = Observation
- 6 = Ratings by Others (include who provided the ratings)
- 7 = Analysis of Written Reports (e.g., diaries or autobiographies)
- 8 = Physiological Measures
- 9 = Objective Measures (e.g., pill bottle count)
- 99 = Other Data Source

*Caution:* The use of a scale does not always mean that the data source is a self-report questionnaire. Often the scales are presented in an interview, making it a self-report interview.

Instrument:    Code: _____    Number of Items: _____							
Reliability:	Coefficients:	MP ____	MP ____	MP ____	MP ____	MP ____	MP ____
Source: _____	Type: _____	_____	_____	_____	_____	_____	_____
Study: _____							

### Coding of the Instrument

#### **Measures of Coping Behaviours**

- 1 = COPE (Carver, Scheier, & Weintraub, 1989)
- 2 = Utrechtse Coping Questionnaire (UCL; Schreurs, & Willige, 1988)
- 3 = Impact of Event Scale - Revised (IES-R; Weiss & Marmar, 1997)
- 4 = Ways of Coping Checklist - Revised (WCCL-R; Vitaliano, Russo, Carr, Maiuro, & Becker)
- 5 = Ways of Coping Questionnaire (WCQ; Folkman & Lazarus, 1988)

#### **Measures of Illness Outcomes**

- 12 = Medical Outcomes Study 36/20/12 Item Short Form (MOS SF-36/20/12; Stewart, Hays, & Ware, 1988)
- 13 = General Health Questionnaire 60/30/28/12 Item (GHQ-60/30/28/12; Goldberg, 1978)
- 14 = Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988)

- 6 = Medication Adherence Reporting Scale - 5 (MARS-5; Horne, 2001)
- 7 = The Morisky Medication Adherence Scale – 8 (MMAS-8; Morisky, Green, & Levine, 1986)
- 8 = Ways of Coping – Cancer Version (WOC-CA; Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992)
- 9 = Cancer Coping Questionnaire (CCQ; Moorey, Frampton, & Greer, 2003)
- 10 = Mental Adjustment to Cancer Scale (or Mini-Mac 1994) (MAC; Watson, Greer, Young, Inayat, Burgess, & Robertson, 1988)
- 11 = Other Measure of Coping Behaviour (Specify)
- 15 = Generalised Anxiety Disorder 7-Item Scale (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006)
- 16 = State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983)
- 17 = Centre for Epidemiological Studies Depression Scale Revised (CESD-R; Eaton, Muntaner, Smith, Tien, & Ybarra, 2004)
- 18 = Patient Health Questionnaire – 2/9 Item (PHQ-9/2; Kroenke, & Spitzer, 2002; Kroenke, Spitzer, & Williams, 2003)
- 19 = Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)
- 20 = Impact of Event Scale – Revised (IES-R; Weiss & Marmar 1996)
- 21 = Psychological Adjustment to Illness Scale – Self Report (PAIS-SR; Derogatis, 1986)
- 22 = Penn State Worry Questionnaire (PSWQ; Meyer, Miller, Metzger, & Borkovec, 1990)
- 23 = Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)
- 24 = Well-being Questionnaire (WB-Q12 or WB-Q22; Bradley, 1994)
- 25 = World Health Organisation Quality of Life (or BREF) (WHOQOL; WHO, 1998)
- 26 = European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30; EORTC 1993)
- 27 = Mental Adjustment to Cancer Scale (or Mini-Mac 1994) (MAC; Watson, Greer, Young, Inayat, Burgess, & Robertson, 1988)
- 28 = Other Measure of Illness Outcome (Specify)

### Number of Items

Number of items specifies the number of items the construct was measured with. If only one subscale is used, only list the number of items for this subscale.

### Source of Reliability Information

- 0 = No Information
- 1 = No Information, but reference to another publication (specify study)
- 2 = Yes, calculated using the sample from this publication (specify values)
- 3 = Yes, calculated using a different sample (values and specify study)

If there is no information about reliability, but there is a reference in the description of the instrument, this corresponds to Coding 1.

If coefficients are drawn from both this sample (coding 2) and from other studies (coding 3) in the publication, only the coefficients of the concrete sample are to be coded.

### Type of Reliability Coefficient

- 1 = Internal Consistency, E.g. Cronbach's  $\alpha$
- 2 = Split- Halves Reliability
- 3 = Test-Retest Reliability
- 4 = Parallel Test Reliability
- 5 = Mean Value of Several Coefficients
- 6 = No Precise Indication
- 99 = Other Coefficient

### MPs for Reliability Coefficients

If a reliability coefficient is given, it is placed in the small table. These should be noted at each MP, for as far as possible. If several reliability coefficients exist for a MP (eg, Cronbach's alpha and split-half coefficient), only report Cronbach's alpha.

If only one reliability coefficient is given for the study, cross out other MP boxes.

If a reliability coefficient is not given, but reference is made to another study, the coefficient from that study should be provided in (beneath) the first MP box, with no number given to the MP itself.

### Study

If a reliability coefficient is (or is not) stated, and reference is made to another study, the first three authors and the year of publication of the study are stated under "Study".





The standardised ( $\beta$ ) and unstandardised ( $B$ ) regression coefficients should be reported here. In addition, the standard error ( $SE$ ), the degrees of freedom ( $df$ ) and p-value ( $p$ ) of the coefficient should be coded.

Source of Statistical Information

Page: \_\_\_\_\_

Table/Graph: \_\_\_\_\_

In order to find the statistical information quickly, record the page number, and if applicable, the number of the table or graph from which the information was collected. If the statistical information was taken from the text, enter “text” here.

Moderator Variables: \_\_\_\_\_

Other Moderator Variables (Authors' Term): \_\_\_\_\_

If Moderator Variables of the relationship between Illness Perceptions and Outcomes have been examined, provide information here.

#### Coding of Moderator Variables

- 1 = Social Support
- 3 = Extraversion
- 4 = Neuroticism
- 5 = Other Personality Characteristics (E.g. Optimism, Self-Esteem, etc.)
- 6 = Previous Experience with Cancer
- 7 = Socio-Economic Status
- 8 = Age
- 9 = Number of Other Illnesses
- 10 = Coping Strategies
- 99 = Other (Specify)

## 8 Concluding Information

Time for Coding: \_\_\_\_\_ minutes

Problems/Comments:

Study Interpretation:

At the end of coding an article, the time needed for encoding should be noted.

In addition, there is space for problems and comments. If information is missing, the missing information should be listed here.

Finally, include a brief interpretation of the study in this box. This can be transcribed or taken directly from the publication abstract.

**Appendix 2.5** Coding sheet (Study 1)

ID No. \_\_\_\_\_

Cancer Type \_\_\_\_\_ DV \_\_\_\_\_

Comments on the study



Study will be Excluded



Write to Authors



Important Comments

General Publication Information

Article Identification Number (ID-No.): \_\_\_\_\_ Study in Article: \_\_\_\_\_

Coder: \_\_\_\_\_ Coding Date \_\_\_\_ / \_\_\_\_ / \_\_\_\_ Time of Day: \_\_\_\_\_

Authors: \_\_\_\_\_ Publication Year: \_\_\_\_\_

Title (first six words): \_\_\_\_\_

Country of Origin - Author: \_\_\_\_\_ Other Origin: \_\_\_\_\_

Discipline of the First Author: \_\_\_\_\_ Other Discipline: \_\_\_\_\_

Publication Found In: \_\_\_\_\_ Other Place Publication Found: \_\_\_\_\_

Type of Publication: \_\_\_\_\_ Other Publication: \_\_\_\_\_ Citations: \_\_\_\_\_ Impact: \_\_\_\_\_

Description of the Study

Study Type: \_\_\_\_\_ IPQ or IPQ-R Dimension: \_\_\_\_\_

Reliability Source: \_\_\_\_\_ Coefficient Type: \_\_\_\_\_ Number of Items: \_\_\_\_\_

Study: \_\_\_\_\_

If Experimental:

Number of Groups: \_\_\_\_\_ Group a: \_\_\_\_\_ Group c: \_\_\_\_\_

Assignment: \_\_\_\_\_ Group b: \_\_\_\_\_ Group d: \_\_\_\_\_

Number of Measurement Points: \_\_\_\_\_ Year of the First Data Collection: \_\_\_\_\_

Lag Between Assessments \_\_\_\_\_: MP 6 \_\_\_\_\_

MP 2 \_\_\_\_\_ MP 7 \_\_\_\_\_

MP 3 \_\_\_\_\_ MP 8 \_\_\_\_\_

MP 4 \_\_\_\_\_ MP 9 \_\_\_\_\_



## Cancer and Sample Information

Type of Sample: _____		
Cancer Type: _____	Cancer Stage: _____	<input type="checkbox"/>
Cancer Duration: M = _____	SD = _____ Range from _____ to _____	<input type="checkbox"/>
Age at Onset: M = _____	SD = _____ Range from _____ to _____	<input type="checkbox"/>
Treatment Type: _____	Treatment Stage: _____	<input type="checkbox"/>
Sample Size at each Measurement Point:		<input type="checkbox"/>
MP 1 _____	MP 5 _____	
MP 2 _____	MP 6 _____	
MP 3 _____	MP 7 _____	
MP 4 _____	MP 9 _____	
Total-N: _____	Retention Rate: _____ %	<input type="checkbox"/>
Proportion of Men at MP 1: _____ %		<input type="checkbox"/>
Age at MP 1: M = _____ SD = _____	Range from _____ to _____	<input type="checkbox"/>
Ethnicity: _____ Other Ethnicity: _____	Country of Origin: _____ Other Country of Origin: _____	<input type="checkbox"/>

## Dependent Variables

No. _____ Did the Study aim to change the Dependent Variable/s? _____							
DV Global: _____ DV Name: _____							
Subscale: _____				DV (Subscale) Type: _____			
Data Source: _____				Additional Info: _____			
Instrument: Code: _____ Number of Items: _____							
Reliability:	Coefficients:	MP ____	MP ____	MP ____	MP ____	MP ____	MP ____
Source: _____	Type: _____	_____	_____	_____	_____	_____	_____
Study: _____							

## Statistical Analyses and Effect Sizes

Type of Statistics Provided: _____											
Means, Standard Deviations, and Standard Errors											
T1 N = _____			T2 N = _____			T3 N = _____			T4 N = _____		
M	SD	SE	M	SD	SE	M	SD	SE	M	SD	SE
T5 N = _____			T6 N = _____			T7 N = _____			T8 N = _____		
M	SD	SE	M	SD	SE	M	SD	SE	M	SD	SE

## Correlations and Reliabilities

Type:	$r_1$ N = _____				$r_2$ N = _____				IPQ Reliability MP _____		IPQ Reliability MP _____	
	$t_1$	$t_2$	$r$	$p$	$t_1$	$t_2$	$r$	$p$	Coeff.	Items	Coeff.	Items
Identity												
Cause (generic)												
Timeline (acute/chronic)												
Timeline Cyclical												
Consequence												
Personal Control												
Treatment Control												
Illness Coherence												
Emotional Representation												

## Regression Coefficients

	Time 1								Time 2							
	Standardised Regression Coefficients				Unstandardised Regression Coefficients				Standardised Regression Coefficients				Unstandardised Regression Coefficients			
	$\beta$	SE	df	$p$	B	SE	df	$p$	$\beta$	SE	df	$p$	B	SE	df	$p$
Identity																
Cause (generic)																
Timeline (acute/chronic)																
Timeline Cyclical																
Consequence																
Personal Control																
Treatment Control																
Illness Coherence																
Emotional Representations																

Source of Statistical Information

Page: \_\_\_\_\_

Table/Graph: \_\_\_\_\_



Moderator Variables

Moderator Variables: \_\_\_\_\_

Other Moderator Variables (Authors' Term): \_\_\_\_\_



Final Details

Time for Coding: \_\_\_\_\_ Minutes

Problems/Comments:



Study Interpretation:



## **Appendix 2.6** Study selection process (Study 1)

Following database screening, 1846 articles were identified, with 983 articles remaining after the removal of duplicates. A title search eliminated 443 studies not meeting the inclusion criteria. The remaining 540 abstracts were screened, and a further 494 of these were excluded for not meeting inclusion criteria. There was a high level of agreement in the abstract screening process between the first and last author, with an inter-rater agreement of 97.59% (Cohen's Kappa = .86). A further four studies were added following a manual search of the reference lists of the 46 studies already identified for inclusion. These 50 studies were coded by the first author using a coding manual and coding sheet (see Appendix 4 and Appendix 5), with a random subsample of studies (20%,  $k = 10$ ) double-coded by the last author. Following coding, five studies that had duplicative data or did not meet the inclusion criteria were excluded.

A second search for relevant literature was conducted in August 2014 using the same process. One hundred and twenty four additional studies were identified, with 49 studies remaining following the removal of duplicates. Of these, 43 did not meet inclusion criteria, based on a high level of agreement between the first and last author, with an inter-rater agreement of 96.49% (Cohen's Kappa = .81). The remaining six studies were again coded by the first author, with a subsample (33.33%,  $k = 2$ ) coded by the last author. Correlations were extracted from a subsample of all studies by the first and last author separately (19.61%,  $k = 5$ ). Out of 101 correlations, 100 were correctly recorded by both researchers (99.01%); the remaining correlation was resolved through discussion and an examination of raw data.

A final search for relevant literature was conducted in March 2015 using the same search strategy. Two hundred and thirty one studies were identified, with 63 studies remaining following the removal of duplicates. Of these, 60 studies did not meet inclusion

criteria, based on high level of agreement between the first and last author (95.24%, Cohen's Kappa = .70). Following coding, the remaining three studies were coded by the first author.

## Appendix 2.7 Quantitative data extraction and study characteristics table (Study 1)

Authors (Date)	Cancer Type	Sample Size (Completed all Time Points)	Sex (T1)	Age (T1)	Study Design	IPQ Type	Coping Behaviour	Illness Outcome	Relevant Results
Beatty and Scott (2013)	Not Specified	88	31% Male	$M = 56.81$ , $SD = 10.67$	Cross-sectional	IPQ-R: Identity, Cause, Consequences	Seeking Social Support, Problem-Focused Coping (Specific-Other) (eHealth Info), Other (eHealth Support)	Psychological Distress	Identity, psychological cause, and consequences were predictive of searching for health-related information online and psychological distress. Cause was also predictive of social support.
Cameron, Booth, Schlatter, Ziginas, Harman, & Benson (2005)	Breast	110	100% Female	$M = 51.48$ , $SD = 9.26$	Cross-sectional	IPQ-R: Cause, Personal Control, Emotional Representations	Seeking Social Support (x2), Avoidance/Denial	Anxiety, Depression	Emotional representations predicted depression, anxiety, and avoidance. Higher personal control was associated with lower depression. Cause (stress) was associated with anxiety.
Chen (2013)	Oral Cavity and Oropharyngeal	103	100% Male	$M = 42.5$	Cross-sectional	IPQ-R: Timeline - Acute/Chronic and Cyclical, Personal and Treatment Control, Consequences	Other (Self-Transcendence)	Depression	Timeline, Consequences, and Control were significant predictors of self-transcendence and depression.
Cook, Salman, Dunn, Holcombe, Cornford, & Fisher (2015)	Not Specified (Breast & Prostate)	229	34% Male	$M = 61.3$ , $SD = 8.9$ , Range = 38 - 85	Cross-sectional	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence		Anxiety, Depression, Psychological Distress (Trauma)	Higher identity, timeline (acute/chronic), consequences, and treatment control (PD only), explained an additional 20%, 18%, and 22% of the variance in anxiety, depression, and psychological distress respectively (controlling for age/gender).
Corter, Findlay, Broom, Porter, & Petrie (2013)	Breast	153	100% Female	Age range: 45 - 61+	Cross-sectional	B-IPQ		Anxiety (Fear of Recurrence)	All illness perceptions (apart from control) were associated with fear of recurrence.
Costanzo, Lutgendorf, & Roeder (2011)	Breast	71	100% Female	$M = 55$ , $SD = 10.8$ , Age range: 32 - 89	Longitudinal	IPQ-R: Cause, Timeline - Acute/Chronic, Consequences, Personal Control	Problem-Focused Coping (Specific-Other) (Decreased Fat Intake, Increased Fruit/Vegetable Intake, Increased Physical Activity, Decreased Alcohol Intake, Increased Stress Reduction)		Women who believed their cancer had more severe consequences and those that attributed the development of cancer to health behaviours or stress, were most likely to report improvements in health behaviours.
Croom (2012)	Not Specified	88	100% Female	$M = 58.2$ , $SD = 11.3$	Cross-sectional	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence		Anxiety, Depression	Illness perceptions predicted anxiety and depression. Identity was the strongest predictor of depression and cyclical timeline the strongest predictor of anxiety.
Croom, Hamann, Kehoe, Paulk, & Wiebe (2013)	Not Specified	105	100% Female	$M = 58.29$ , $SD = 11.05$ , Age range: 24-83	Cross-sectional	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence	Problem-Focused Coping (Generic) (Advanced-Illness Behaviours)	Quality of Life	Illness perception variables accounted for a large proportion of the variance for QOL and advanced-illness behaviours, with identity the strongest predictor of QOL and chronic timeline the strongest predictor of advanced-illness behaviours.

Dempster, McCorry, Brennan, Donnelly, Murray, & Johnston (2012)	Oesophageal	484	66% Male	$M = 65, SD = 9.94$	Cross-sectional	IPQ-R: Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Anxiety, Depression	Several illness perceptions predicted anxiety and depression. Consequences was the strongest predictor, with more severe consequences associated with higher levels of anxiety and depression.	
Donovan (2003)	Ovarian	713	100% Female	Total: $M = 53.42, SD = 48.94$ , Range = 22-91	Cross-sectional	Problem-Focused Coping (Generic) (Coping)	Treatment Related Distress, Psychological Well-Being (Life Satisfaction)	Illness perceptions predicted problem-focused coping, treatment related distress, and psychological well-being. Identity was the strongest predictor of all three outcomes.	
Duric, Butow, Sharpe, Boyle, Beith, Wilcken, Heritier, Coates, Simes, & Stockler (2007)	Breast	83	100% Female	$M = 55$ , Range = 25-73	Cross-sectional	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Treatment Decision Making (Preferences - small benefits of adjuvant chemotherapy), Treatment Decision Making (Preferences - negligible benefits of adjuvant chemotherapy)	Depression, Treatment Related Distress	Identity and consequences were associated with treatment decision making, treatment related distress, and depression.
Fan, Eiser, Ho, & Lin (2013)	Liver (Hepatocellular Carcinoma)	286	76.22% Male	$M = 59.85, SD = 12.16$ , Range = 25.46 - 84.81	Cross-sectional	B-IPQ	Problem-Focused Coping (Generic), Other (Emotion-Focused Coping)	Psychological Distress (Emotional Functioning), Physical Functioning, Quality of Life (Health-Related)	Cognitive representations (combined) and emotional representations predicted global HRQOL, physical functioning, and emotional functioning.
Fischer, Wiesenhaan, Heijer, Kleijn, Nortier, & Kaptein (2013)	Breast	57	100% Female	$M = 50.7, SD = 6.9$ , Range = 37 - 72	Longitudinal	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Problem-Focused Coping (Generic), Other (Emotional Support), Avoidance/Denial, Cognitive Reappraisal	Psychological Distress	Several illness perception dimensions predicted each coping outcome. All illness perceptions other than control (personal and treatment) predicted psychological distress.
Förster & Taubert (2006)	Not Specified	156	58.3% Male	$M = 63, SD = 10.5$ , Range = 34 - 86	Longitudinal	IPQ-R: Cause, Timeline - Acute/Chronic, Personal Control	Problem-Focused Coping (Generic), Cognitive Reappraisal (x2), Other (Self-Blame)	Depression, Quality of Life, Disease State	Control beliefs were predictive of adaptive coping behaviours (problem-solving, reappraisal). Shorter timeline predicted higher levels of quality of life.
Foster, Breckons, Cotterell, Barbosa, Calman, Corner, Fenlon, Foster, Grimmett, Richardson, & Smith (2015)	Not Specified	182	80.8% Female	$M = 50, SD = 9.51$ , Range = 23 - 79	Cross-sectional	B-IPQ: Identity, Timeline - Acute/Chronic, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Other (Self-Efficacy)	Individuals most likely to report low self-efficacy included those with an overall more negative perception of cancer.
Freeman-Gibb (2012)	Breast	107	100% Female	Range = 26 - 75	Cross-sectional	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Other (Cognitive Coping Strategies), Other (Self-Blame), Avoidance/Denial, Cognitive Reappraisal	Anxiety (x2) (Fear of Recurrence)	Several illness perception dimensions predicted trait anxiety and each coping outcome. Fear of cancer recurrence was related to emotional representations, timeline (acute/chronic), perceived consequences/severity, and symptom attribution (identity).

Gibbons (2013)	Breast	57	100% Female	$M = 56.35$ , $SD = 5.20$ , Range = 40 - 77	Longitudinal	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Cognitive Reappraisal, Other (Fatalism), Avoidance/Denial	Psychological Distress (Perceived Stress), Anxiety (x3) (State), Depression, Psychological Distress (x2) (Cancer-related), Psychological Distress (Helplessness - Hopelessness)	Illness perceptions are important predictors of distress and coping outcomes over the first 12 months after a diagnosis of breast cancer.
Gould, Brown, & Bramwell (2010)	Other Gynaecological	61	100% Female	$M = 56.34$ , $SD = 18.41$	Cross-sectional	IPQ-R: Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence	Problem-Focused Coping (Generic), Other (Emotion/social support), Avoidance/Denial, Cognitive Reappraisal, Other (Religion)	Affect	Several illness perceptions were associated with each coping outcome. Illness coherence and consequences were the strongest predictors of affect.
Green, Steinnagel, Morris, & Laakso (2014)	Not Specified (Breast and Prostate)	237	61.2% Female	$M = 60.60$ , $SD = 9.55$ , Range = 32 - 84	Cross-sectional	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Problem-Focused Coping (Specific-Other) (Nutrition, Physical Activity)		Illness perception dimensions did not seem to predict nutrition in this sample. However, identity, personal control, and illness coherence predicted nutrition.
Henselmans, Sanderman, Helgeson, de Vries, Smink, & Ranchor (2010)	Breast	133	100% Female	$M = 57$ , $SD = 9$	Longitudinal	IPQ-R: Personal Control		Depression, Anxiety (State), Role Functioning (Threat Appraisal), Anxiety (Worry)	A strong sense of control over the cure of breast cancer predicted lower depression, state anxiety, threat appraisal, and worry.
Hopman & Rijken (2014)	Not Specified	267	50.46% Female	$M = 64.31$ , $SD = 12.21$ , Range = 21 - 89	Cross-sectional	IPQ-R: Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Cognitive Reappraisal, Other (Fatalism), Avoidance/Denial	Anxiety, Psychological Distress (Helplessness - Hopelessness)	More passive ways of coping were more often found in patients who perceived their illness as long lasting, more emotionally burdening, and having more negative consequences.
Karademas & Giannousi (2013)	Not Specified	72	55.56% Male	$M = 55.01$ , $SD = 13.29$ , Range = 31 - 74	Cross-sectional	IPQ-R: Personal Control, Treatment Control		Anxiety, Depression, Quality of Life	Findings suggest that both representations of control (personal and treatment) are important for adaptation to illness. With higher levels of personal and treatment control associated with lower levels of anxiety and depression.
Keeling, Bambrough, & Simpson (2013)	Brain	74	52.70% Female	$M = 38.30$ , $SD = 10.67$	Cross-sectional	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Anxiety, Depression, Affect (Positive)	Illness perceptions play a significant role in emotional distress experienced by people with low-grade brain tumours but did not play such a role in positive affect.
Llewellyn, McGurk, & Weinman (2006)	Head and Neck	55	65% Male	$M = 59$ , $SD = 13.4$ , Range = 23 - 89	Cross-sectional	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Illness Coherence, Emotional Representations		Quality of Life (Individualised), Physical Functioning (x2), Psychological Distress (Emotional Functioning), Role Functioning (x2) (Social Functioning) (Cognitive Functioning), Other (General Health), Vitality, Psychological	Several illness perception dimensions predicted several health outcomes. Higher emotional representations predicted poorer QOL, and higher levels of anxiety and depression.



							Well-being, Anxiety, Depression		
Author(s)	Location	N	Gender	Mean (SD), Range	Design	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Illness Coherence, Emotional Representations	Cognitive Reappraisal (x3), Problem-Focused Coping (Generic) (x2), Avoidance/Denial (x2), Other (Substance Use), Seeking Social Support (x2), Expressing Emotion, Other (Humour), Other (Religion), Other (Self-Blame)	Physical Functioning, Psychological Well-being (Mental Component Summary), Quality of Life	Illness perceptions predicted several health and coping outcomes. Emotional representations was often the highest or one of the highest predictors of the various outcomes.
Llewellyn, McGurk, & Weinman (2007)	Head and Neck	82	66% Male	$M = 59.9, SD = 12.5, \text{Range} = 23 - 89$	Cross-sectional	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Illness Coherence, Emotional Representations			
Llewellyn, Weinman, McGurk, & Humphris (2008)	Head and Neck	50	66% Male	$M = 59.9, SD = 12.5, \text{Range} = 23 - 89$	Longitudinal	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Illness Coherence, Emotional Representations		Anxiety (Fear of Recurrence)	Emotional representations and consequences were the highest predictors of fear of recurrence, with higher levels leading to more fear.
McCorry, Dempster, Quinn, Hogg, Newell, Moore, Kelly, & Kirk (2013)	Breast	75	100% Female	$M = 57.2, SD = 10.4$	Longitudinal	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Anxiety, Depression	Emotional representations and consequences were the highest predictors of both anxiety and depression, with higher levels of each leading to more anxiety and depression.
Mols, Lemmens, Bosscha, van den Broek, & Thong (2014)	Rectal	1019 (538 no ostomy, 408 ostomy)	58.77% Male [56.1% Male (no ostomy), 62.3% Male (ostomy)]	Median = 68.72 [Median = 67.0 (no ostomy), Median = 69.8 (ostomy)]	Cross-sectional	B-IPQ: Identity, Timeline - Acute/Chronic, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Anxiety, Depression, Quality of Life, Physical Functioning, Role Functioning (x3) (Cognitive Functioning), (Social Functioning), Psychological Distress (Emotional Functioning)	Those survivors with or without an ostomy had several illness perceptions related to functioning. However, survivors with an ostomy believed that their illness has significantly more serious consequences, will last longer, and were more concerned about their illness.
Paschali, Hadjulis, Papadimitriou, & Karademas (2015)	Not Specified	93	43.01% Male	$M = 58.34, SD = 11.18$	Cross-sectional	IPQ-R: Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Problem-Focused Coping (Generic) (Positive Adjustment to Cancer), Avoidance/Denial (Negative Adjustment to Cancer)	Physical Functioning	Several illness perceptions were related to physical functioning, positive adjustment to cancer, and negative adjustment to cancer.
Rozema, Völlink, & Lechner (2009)	Breast	119	100% Female	$M = 46.8, SD = 8.21, \text{Range} = 22 - 64$	Cross-sectional	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Emotional Representations	Problem-Focused Coping (Generic), Avoidance/Denial (x2), Seeking Social Support, Expressing Emotion	Physical Functioning (Physical Health), Psychological Well-being (Mental Health)	Patients who view their illness as a condition with serious symptoms (identity) and consequences, a chronic timeline, and who view their illness as uncontrollable were found to report worse physical and mental health.
Scharloo, Baatenburg de Jong, Langeveld, van Velzen-Verkaik, Doorn-	Head and Neck	95	64.89% Male	$M = 59.5, SD = 11.3, \text{Range} = 28 - 84$	Longitudinal	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control,		Quality of Life, Physical Functioning, Role Functioning (x3) (Cognitive Functioning), (Social Functioning),	Illness perceptions were related to functioning. The strongest predictor of functioning was generally identity, with higher levels associated with poorer functioning.

op den Akker, & Kaptein (2010)						Illness Coherence, Emotional Representations		Psychological Distress (Emotional Functioning)	
Silva, Moreira, & Canavarro (2012)	Breast	78	100% Female	<i>M</i> = 52.08, <i>SD</i> = 8.86, Range = 30 - 68	Cross-sectional	B-IPQ: Consequences	Cognitive Reappraisal (Posttraumatic Growth)	Anxiety, Depression, Physical Functioning (Physical QOL), Psychological Well-being (Psychological QOL), Role Functioning (Social QOL)	A more negative perception of the impact of breast cancer was significantly associated with higher emotional distress and impaired physical and psychological QOL, but was unrelated to posttraumatic growth.
Thune-Boyle, Myers, & Newman (2006)	Not Specified	72	54% Female	<i>M</i> = 56, Range = 22 - 83	Cross-sectional	IPQ: Consequences, Cure/Control		Anxiety, Depression	More severe consequences predictor higher levels of both anxiety and depression.
Traeger (2009)	Prostate	261	100% Male	<i>M</i> = 65.4, <i>SD</i> = 7.6	Cross-sectional	IPQ-R: Consequences		Role Functioning (x3) (Sexual Bother) (Sexual Function) (Social WB), Quality of Life (Health-Related), Other (General Health), Physical Functioning (x2) (Functional WB), Psychological Distress (Emotional WB)	More severe consequences predicted worse functioning and a poorer QOL.
Traeger, Penedo, Gonzalez, Dahn, Lechner, Schneiderman, & Antoni (2009)	Prostate	214	100% Male	<i>M</i> = 64.9, <i>SD</i> = 7.4	Cross-sectional	IPQ-R: Cause, Consequences, Personal Control, Treatment Control, Illness Coherence		Psychological Distress (x2) (Life Stress) (Emotional WB), Role Functioning (Sexual Function)	More severe perceived consequences of prostate cancer were associated with poorer emotional well-being, particularly among men experiencing greater life stress.
Van Der Kloot, Kobayashi, Yamaoka, Inoue, Nortier, & Kaptein (2014)	Not Specified (Breast & Lung)	80	62.92% Female	<i>M</i> = 55.99, <i>SD</i> = 8.53	Longitudinal	B-IPQ: Identity, Timeline - Acute/Chronic, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Quality of Life, Role Functioning (x2) (Social Functioning) (Physical and Role Functioning), Psychological Distress (Psychological Functioning)	Illness perceptions were related to functioning. The strongest predictors of functioning were generally identity, consequences, and emotional representations.
Wu, Mohamed, Winkel, & Diefenbach (2013)	Prostate	53	100% Male	<i>M</i> = 64.52, <i>SD</i> = 9.02, Range = 43 - 84 (For the TOTAL sample - 53 - NOT at T1)	Longitudinal	IPQ-R: Timeline - Acute/Chronic, Treatment Control		Quality of Life	A more chronic timeline and higher levels of treatment control were associated with better QOL, but not significantly.
Živkovic, Buljan, Blajic, & Situm (2008)	Melanoma Skin Cancer	60	56.67% Female	<i>M</i> = 52, Range = 29 - 74	Cross-sectional	B-IPQ		Quality of Life (x2) (Subjective QOL) (The Impact of Illness on QOL), Depression	Several illness perception dimensions are correlated with patients' QOL, the influence illness has on QOL, and depression.

## Appendix 2.8 Qualitative data extraction and study characteristics table (Study 1)

Authors (Date)	Cancer Type	Sample Size All Time Points	Sex (T1)	Age (T1)	Study Design	IPQ Type	Coping Behaviour	Illness Outcome	Relevant Results
Cook, Salman, Dunn, Holcombe, Cornford, & Fisher (2015)	Not Specified (Breast & Prostate)	206	35.44% Male (final sample - T2)	$M = 61.50$ , $SD = 9.00$ , Range = 39 - 85 (final sample - T2)	Longitudinal	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence		Anxiety, Depression, Psychological Distress (Trauma)	Illness perceptions at T1 predicted between 10% for trauma and 12% for anxiety of the variance in T2 outcomes (controlling for age/gender). Perceived lack of personal control and a perception of more serious consequences predicted T2 anxiety, while less illness coherence predicted T2 depression and trauma.
Cooper, Hankins, Rixon, Eaton, & Grunfeld (2013)	Breast, Gynaecological, Prostate, Head and Neck	Breast (89), Gynaecological (56), Prostate (88), Head and Neck (47)	Breast (100% Female), Gynaecological (100% Female), Prostate (100% Male), Head and Neck (74.5% Male)	Breast ( $M = 49$ , $SD = 7$ ), Gynaecological ( $M = 48$ , $SD = 10$ ), Prostate ( $M = 54$ , $SD = 11$ ), Head and Neck ( $M = 52$ , $SD = 9$ )	Longitudinal	IPQ-R: Timeline - Acute/Chronic, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Role Functioning (Return to Work)	Consequences were associated with return to work in those with breast cancer and head and neck cancer. Personal control was associated with return to work in those with gynaecological cancer.
Dempster, McCorry, Brennan, Donnelly, Murray, & Johnston (2011)	Oesophageal	189	74.07% Male	$M = 64.8$ , $SD = 8.83$	Longitudinal	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Anxiety, Depression	Several illness perception dimensions predicted anxiety and depression over a 12 month period.
Giannousi, Manaras, Georgoulas, & Samonis (2010)	Not Specified	206	66% Female	$M = 55$ , $SD = 12.53$	Cross-sectional	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Depression	Multiple regression analysis showed that consequences, emotional representations, illness identity, and psychological attributions were the best predictors for depression.
Grande, Arnott, Brundle, & Pilling (2014)	Not Specified	43	61.3% Male	$M = 66.48$ , $SD = 8.95$	Longitudinal	IPQ-R: Personal Control, Emotional Representations	Seeking Social Support (x2)		Emotional representations significantly predicted support group participation.
Grande, Myers, & Sutton (2006)	Not Specified	SG-Y = 63, SG-N = 44	SG-Y = 16.1%, SG-N = 38.6%	SG-Y Median = 61 (IQR = 15.3), SG-N Median = 64.5 (IQR = 18.8)	Cross-sectional	IPQ-R: Personal Control, Emotional Representations	Seeking Social Support		Support group participants felt more control over their cancer, but were more distressed and anxious (higher emotional representations).
Gray, Hall, Browne, Johnston, Lee, Macleod, Mitchell, Samuel, & Campbell (2014)	Colorectal	496	55% Male	$M = 66$ , $SD = 11.11$	Cross-sectional	IPQ-R: Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Anxiety, Depression	Reporting a high negative life and emotional impact (emotional representations) predicted anxiety caseness and increased the odds of depression caseness.
Gray, Hall, Browne, Macleod, Lee, Johnston, Wyke, Samuel, Weller, & Campbell (2011)	Colorectal	496	55% Male	$M = 66$ , $SD = 11.11$	Cross-sectional	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Quality of Life	Higher identity, cyclical timeline, and consequences were predictive of lower QOL, while higher personal and treatment control was associated with higher QOL.

Iskandarsyah, de Klerk, Suardi, Sadarjoen, & Passchier (2014)	Breast	70	100% Female	$M = 45.6, SD = 7.88, \text{Range} = 28 - 66$	Cross-sectional	B-IPQ: Identity, Timeline - Acute/Chronic, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations	Adherence to Treatment Visits (x2)		More negative illness perceptions and whether a traditional healer had been consulted after diagnosis were associated with missing treatment sessions. Treatment related distress was most closely associated with missing treatment sessions. Baseline analysis showed that illness perceptions were associated with distress and QOL. Consequences and treatment control were associated with QOL, while cause (stress or worry) and emotional representations were associated with distress.
Jørgensen, Frederiksen, Boesen, Elsass, & Johansen (2009)	Breast	177	100% Female	$M = 53.27, \text{Range} = 25 - 74$	Experimental	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Consequences, Personal Control, Treatment Control, Emotional Representations		Quality of Life, Psychological Distress (Emotional Distress)	Respondents reporting more bowel symptoms (identity) and high timeline cyclical scores were more likely to use certain self-care strategies.
Landers, McCarthy, Livingstone, & Savage (2014)	Rectal	143	61.5% Male	$\text{Range} = 35 - 80$	Cross-sectional	IPQ: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclic, Consequences, Personal Control, Treatment Control, Emotional Representations	Problem-Focused Coping (Specific) (x3), Medication Adherence		Beliefs about the chronicity of the disease (timeline beliefs) were predictors of depression after treatment.
Llewellyn, McGurk, & Weinman (2007)	Head and Neck	50	66% Male	$M = 59.9, SD = 12.5, \text{Range} = 23 - 89$	Longitudinal	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Illness Coherence, Emotional Representations	Multiple	Multiple - e.g. Depression	Several illness perception dimensions were associated with functioning. Consequences were often the strongest predictor of functioning.
Mičkevičienė, Vanagas, Jievalta, & Ulys, (2013)	Prostate	501	100% Male	$M = 69.3, SD = 8.8$	Cross-sectional	IPQ-R: Identity, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Quality of Life, Physical Functioning, Role Functioning (x3) (Cognitive Functioning) (Social Functioning), Psychological Distress (Emotional Functioning)	Psychological morbidity (distress) in the year following breast cancer surgery is reliably predicted by the patient's perception of the impact of the symptoms (identity) and the timeline of the disease.
Millar, Purushotham, McLatchie, George, & Murray (2005)	Breast	213	100% Female	$M = 59.4, SD = 10.9, \text{Range} = 29 - 98$	Longitudinal	IPQ: Identity, Timeline, Consequences, Cure/Control		Psychological Distress	Illness perceptions were significantly related to the QLQ-C30 physical, role, emotional, cognitive, social functioning, and global health scales.
Scharloo, Baatenburg de Jong, Langeveld, van Velzen-Verkaik, Doornop den Akker, & Kaptein (2005)	Head and Neck	68	58.33% Male	$M = 60, \text{Range} = 41 - 84$	Cross-sectional	IPQ-R: Identity, Cause, Timeline - Acute/Chronic, Timeline - Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence, Emotional Representations		Quality of Life, Physical Functioning, Role Functioning (x3) (Cognitive Functioning) (Social Functioning), Psychological Distress (Emotional Functioning)	For men reporting higher stress upon study entry, Cognitive-Behavioural Stress Management (intervention) related improvements were partially explained by changes in some illness perceptions.
Traeger, Penedo, Benedict, Dahn, Lechner, Schneiderman, & Antoni (2013)	Prostate	257	100% Male	$M = 65.3, SD = 7.7$	Experimental	IPQ-R: Cause, Consequences, Personal Control, Treatment Control, Illness Coherence		Psychological Distress (x2) (Emotional WB) (Life Stress), Role Functioning (x2) (Sexual Function) (Urinary Function)	

## Appendix 2.9 Meta-analytic strategy – additional information (Study 1)

Zero-order correlations were the most frequently reported effect size, and therefore the average correlation coefficient weighted by sample size and calculated using Fischer's  $Z$  transformations ( $r_z$ ) was used as the measure of effect in the meta-analysis. Correlations were reversed where necessary to maintain consistency across studies (e.g., when measuring emotional functioning rather than psychological distress). If a study used more than one measure to assess an outcome within the same category (e.g., generalised anxiety and trait anxiety), the smallest correlation coefficient was used in order to obtain a more conservative estimate of the correlation and to avoid bias. Further, if a study measured an outcome at more than one time point, only the Time 1 (baseline) result was used to minimise heterogeneity due to design. Authors of papers that did not report correlations were contacted. A qualitative narrative review was conducted for studies that did not include sufficient data and where data could not be obtained.

To examine heterogeneity between studies,  $Q$  and  $I^2$  statistics were calculated. The  $Q$  statistic assesses the ratio of the variation in the observed effects to the within-study error, and suggests heterogeneity when statistically significant (Huedo-Medina, Sanchez-Meca, Marin-Martinez, & Botella, 2006). The  $I^2$  statistic indicates the percentage of variance across studies that is due to heterogeneity rather than chance, with increasing values meaning increasing heterogeneity. This, the  $I^2$  statistic gives an indication of the extent of true heterogeneity, whereas the  $Q$  statistic only provides an indication of statistical significance. It has been suggested that an  $I^2$  value of 25% is low, 50% is moderate, and 75% is high (Higgins, Thompson, Deeks, & Altman, 2003).

In a meta-analysis, no matter how systematic the search process, there is always the chance that the results will be biased due to unpublished, missing, or otherwise unidentified

studies that potentially report non-significant or even contrary findings. This phenomenon was described by Rosenthal (1979) as the ‘file drawer problem’, and suggests that there may be a range of unpublished studies living in the file drawers of researchers. One of the implications of this problem is that there is a publication bias towards results that are statistically significant or that have larger effect sizes. Funnel plots and the ‘fail-safe N’ ( $N_{fs}$ ) were used to assess this risk of bias. Funnel plots display the relationship between effect size and standard error (sample size) (Light & Pillemer, 1984), while the Rosenthal method for calculating fail-safe N was applied. This method results in the provision of the number of studies with non-significant results that would need to be found to reduce the effect size of the present meta-analysis to a negligible level (Rosenthal, 1979).

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**Appendix 2.10** Risk of bias assessment (Study 1)

<b>Authors (Date)</b>	<b>Study Design</b>	<b>IPQ, IPQ-R, or B-IPQ: Used as recommended</b>	<b>Dimensions assessed (number of items)*</b>	<b>Correlation Analysis</b>	<b>Adjustment for possible confounds</b>	<b>Meta-Analysis or Narrative Review</b>
Beatty and Scott (2013)	Cross-sectional	IPQ-R: Yes - ‘cancer’ substituted for ‘illness’	Identity (14), Cause (6), Consequences (6)	Spearman’s Correlation	None	Meta-Analysis
Cameron, Booth, Schlatter, Ziginskis, Harman, & Benson (2005)	Cross-sectional	IPQ-R: Partially - shortened versions of scales were used - ‘breast cancer’ substituted for ‘illness’	Cause (2), Personal Control (3), Emotional Representations (4)	Pearson’s Correlation	None	Meta-Analysis
Chen (2013)	Cross-sectional	IPQ-R: Yes	Timeline - Acute/Chronic and Cyclical (10), Personal and Treatment Control (11), Consequences (6)	Pearson’s Correlation	None	Meta-Analysis
Cook, Salman, Dunn, Holcombe, Cornford, & Fisher (2015)	Longitudinal	IPQ-R: Yes - several cause items removed	Identity (14), Cause (7), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5)	N/A	N/A	Narrative Review
Cook, Salman, Dunn, Holcombe, Cornford, & Fisher (2015)	Cross-sectional	IPQ-R: Yes - one identity item added - several cause items removed	Identity (15), Cause (7), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5)	Pearson’s Correlation	None	Meta-Analysis
Cooper, Hankins, Rixon, Eaton, & Grunfeld (2013)	Longitudinal	IPQ-R: Partially - adapted for cancer patients - additional items added to some subscales	Timeline - Acute/Chronic (5), Consequences (6), Personal Control (5), Treatment Control (7), Illness Coherence (5), Emotional Representations (6)	N/A	N/A	Narrative Review
Corter, Findlay, Broom, Porter, & Petrie (2013)	Cross-sectional	B-IPQ: Yes - ‘breast cancer’ substituted for ‘illness’	Identity (1), <b>Cause (1)</b> , Timeline - Acute/Chronic (1), Consequences (1), Personal Control (1), Treatment Control (1), Illness Coherence (1), Emotional Representations (2)	Spearman’s Correlation	None	Meta-Analysis

Costanzo, Lutgendorf, & Roeder (2011)	Longitudinal	IPQ-R: Yes - cause items were adapted to suit breast cancer	Cause (13), Timeline - Acute/Chronic (6), Consequences (6), Personal Control (6)	Pearson's Correlation	None	Meta-Analysis
Croom (2012)	Cross-sectional	IPQ-R: Partially - additional items added to some subscales - 'cancer' substituted for 'illness'	Identity (15), Timeline - Acute/Chronic (8), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (6), Illness Coherence (5)	Pearson's Correlation	- Relationship Length - Income - The Eastern Cooperative Oncology Group (ECOG) Performance Status	Meta-Analysis
Croom, Hamann, Kehoe, Paulk, & Wiebe (2013)	Cross-sectional	IPQ-R: Yes - one identity item added	Identity (15), Timeline - Acute/Chronic (8), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (6), Illness Coherence (5)	Pearson's Correlation	None	Meta-Analysis
Dempster, McCorry, Brennan, Donnelly, Murray, & Johnston (2012)	Cross-sectional	IPQ-R: Yes - cause items were adapted following factor analysis	Cause (18), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5)	Point-Biserial Correlation	None	Meta-Analysis
Dempster, McCorry, Brennan, Donnelly, Murray, & Johnston (2011)	Longitudinal	IPQ-R: Yes - cause items were adapted following factor analysis	Identity, (14), Cause (18), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	N/A	N/A	Narrative Review
Donovan (2003)	Cross-sectional	IPQ-R: Yes - several identity items added	Identity, (22), Cause (6), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Duric, Butow, Sharpe, Boyle, Beith, Wilcken, Heritier, Coates, Simes, & Stockler (2007)	Cross-sectional	IPQ-R: Yes - items were adapted to suit breast cancer	Identity (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis



Fan, Eiser, Ho, & Lin (2013)	Cross-sectional	B-IPQ: Yes	Identity (1), Cause (1), Timeline - Acute/Chronic (1), Consequences (1), Personal Control (1), Treatment Control (1), Illness Coherence (1), Emotional Representations (2)	Pearson's Correlation	None	Meta-Analysis
Fischer, Wiesenhaan, Heijer, Kleijn, Nortier, & Kaptein (2013)	Longitudinal	IPQ-R: Yes	Identity (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Förster & Taubert (2006)	Longitudinal	IPQ-R: Partially - shortened versions of scales were used	Cause (7), Timeline - Acute/Chronic (2), Personal Control (1)	Lagged Correlation	None	Meta-Analysis
Foster, Breckons, Cotterell, Barbosa, Calman, Corner, Fenlon, Foster, Grimmett, Richardson, & Smith (2015)	Cross-sectional	B-IPQ: Yes	Identity (1), Timeline - Acute/Chronic (1), Consequences (1), Personal Control (1), Treatment Control (1), Illness Coherence (1), Emotional Representations (2)	Pearson's Correlation	None	Meta-Analysis
Freeman-Gibb (2012)	Cross-sectional	IPQ-R: Yes - several identity items added - cause items were adapted to suit breast cancer	Identity (20), <b>Cause (18)</b> , Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Giannousi, Manaras, Georgoulas, & Samonis (2010)	Cross-sectional	IPQ-R: Partially - scales underwent factor analysis and were changed accordingly - several identity items added - cause items were adapted following factor analysis	Identity (22), Cause (13), Timeline - Acute/Chronic (7), Timeline - Cyclical (3), Consequences (8), Personal Control (6), Treatment Control (4), Illness Coherence (4), Emotional Representations (8)	None	None	Narrative Review

Gibbons (2013)	Longitudinal	IPQ-R: Yes - 'breast cancer' substituted for 'illness' - several identity items added - cause items were adapted to suit breast cancer	Identity (19), Cause (17), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Gould, Brown, & Bramwell (2010)	Cross-sectional	IPQ-R: Yes - 'cancer' substituted for 'illness'	Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5)	Pearson's Correlation	- Age - Time Since - Diagnosis - Cancer Stage - Cancer Site	Meta-Analysis
Grande, Arnott, Brundle, & Pilling (2014)	Longitudinal	IPQ-R: Yes	Personal Control (6), Emotional Representations (6)	N/A	N/A	Narrative Review
Grande, Myers, & Sutton (2006)	Cross-sectional	IPQ-R: Yes - 'cancer' substituted for 'illness'	Personal Control (6), Emotional Representations (6)	N/A	N/A	Narrative Review
Gray, Hall, Browne, Johnston, Lee, Macleod, Mitchell, Samuel, & Campbell (2014)	Cross-sectional	IPQ-R: Yes	Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	N/A	N/A	Narrative Review
Gray, Hall, Browne, Macleod, Lee, Johnston, Wyke, Samuel, Weller, & Campbell (2011)	Cross-sectional	IPQ-R: Yes	Identity (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	N/A	N/A	Narrative Review
Green, Steinnagel, Morris, & Laakso (2014)	Cross-sectional	IPQ-R: Yes	Identity (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Unspecified Correlation	None	Meta-Analysis
Henselmans, Sanderman, Helgeson, de Vries, Smink, & Ranchor (2010)	Longitudinal	IPQ-R: Yes - 'breast cancer' substituted for 'illness'	Personal Control (6)	Pearson's Correlation	None	Meta-Analysis

Hopman & Rijken (2014)	Cross-sectional	IPQ-R: Yes	Cause (18), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Iskandarsyah, de Klerk, Suardi, Sadarjoen, & Passchier (2014)	Cross-sectional	B-IPQ: Yes	Identity (1), Timeline - Acute/Chronic (1), Consequences (1), Personal Control (1), Treatment Control (1), Illness Coherence (1), Emotional Representations (2)	N/A	N/A	Narrative Review
Jørgensen, Frederiksen, Boesen, Elsass, & Johansen (2009)	Experimental	IPQ-R: Yes - several cause items removed	Identity (14), Cause (3), Timeline - Acute/Chronic (6), Consequences (6), Personal Control (6), Treatment Control (5), Emotional Representations (6)	N/A	N/A	Narrative Review
Karademas & Giannousi (2013)	Cross-sectional	IPQ-R: Yes	Personal Control (6), Treatment Control (5)	Unspecified Correlation	None	Meta-Analysis
Keeling, Bambrough, & Simpson (2013)	Cross-sectional	IPQ-R: Yes - several identity items added - cause items were adapted following factor analysis	Identity (22), Cause (21), <b>Timeline - Acute/Chronic (6)</b> , Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), <b>Emotional Representations (6)</b>	Pearson's Correlation	None	Meta-Analysis
Landers, McCarthy, Livingstone, & Savage (2014)	Cross-sectional	IPQ: Partially - scales were adapted for cancer patients - several cause items removed	Identity (12), Cause (10), IPQ-R: Timeline - Acute/Chronic (6), Timeline - Cyclic (4), Consequences (6), Personal Control (6), Treatment Control (5), Emotional Representations (6)	N/A	N/A	Narrative Review
Llewellyn, McGurk, & Weinman (2006)	Cross-sectional	IPQ-R: Yes	<b>Identity (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Illness Coherence (5), Emotional Representations (6)</b>	Pearson's Correlation	None	Meta-Analysis

Llewellyn, McGurk, & Weinman (2007)	Cross-sectional	IPQ-R: Yes	Identity (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Llewellyn, McGurk, & Weinman (2007)	Longitudinal	IPQ-R: Yes	Identity (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Illness Coherence (5), Emotional Representations (6)	N/A	N/A	Narrative Review
Llewellyn, Weinman, McGurk, & Humphris (2008)	Longitudinal	IPQ-R: Yes	Identity (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
McCorry, Dempster, Quinn, Hogg, Newell, Moore, Kelly, & Kirk (2013)	Longitudinal	IPQ-R: Yes - cause items were adapted following factor analysis	Identity (14), <b>Cause (18)</b> , Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Mičkevicienė, Vanagas, Jievalta, & Ulys, (2013)	Cross-sectional	IPQ-R: Yes	Identity (14), Timeline - Acute/Chronic (6), Timeline -Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	N/A	N/A	Narrative Review
Millar, Purushotham, McLatchie, George, & Murray (2005)	Longitudinal	IPQ: Yes	Identity (12), Timeline (3), Consequences (7), Cure/Control (6)	N/A	N/A	Narrative Review
Mols, Lemmens, Bosscha, van den Broek, & Thong (2014)	Cross-sectional	B-IPQ: Yes	Identity (1), Timeline - Acute/Chronic (1), Consequences (1), Personal Control (1), Treatment Control (1), Illness Coherence (1), Emotional Representations (2)	Pearson's Correlation	None	Meta-Analysis

Paschali, Hadjulis, Papadimitriou, & Karademas (2015)	Cross-sectional	IPQ-R: Yes - cause items were adapted to suit cancer	Cause (13), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Rozema, Völlink, & Lechner (2009)	Cross-sectional	IPQ-R: Partially - scales were adapted for breast cancer patients - several identity items added - cause items were adapted following factor analysis	Identity (17), Cause (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Scharloo, Baatenburg de Jong, Langeveld, van Velzen-Verkaik, Doorn-op den Akker, & Kaptein (2010)	Longitudinal	IPQ-R: Partially - cause items were adapted to suit the sample (though not using a formal factor analysis)	Identity (14), Cause (5), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Scharloo, Baatenburg de Jong, Langeveld, van Velzen-Verkaik, Doorn-op den Akker, & Kaptein (2005)	Cross-sectional	IPQ-R: Partially - cause items were adapted to suit the sample (though not using a formal factor analysis)	Identity (14), Cause (5), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	N/A	N/A	Narrative Review
Silva, Moreira, & Canavarro (2012)	Cross-sectional	B-IPQ: Yes	Consequences (1)	Pearson's Correlation	None	Meta-Analysis
Thune-Boyle, Myers, & Newman (2006)	Cross-sectional	IPQ: Partially - scales were adapted for breast cancer patients	Consequences (7), Cure/Control (6)	Pearson's Correlation	None	Meta-Analysis
Traeger (2009)	Cross-sectional	IPQ-R: Yes	Consequences (6)	Unspecified Correlation	None	Meta-Analysis
Traeger, Penedo, Benedict, Dahn, Lechner, Schneiderman, & Antoni (2013)	Experimental	IPQ-R: Partially - cause items were adapted based on previous research (not through a formal factor analysis)	Cause (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5)	N/A	N/A	Narrative Review

Traeger, Penedo, Gonzalez, Dahn, Lechner, Schneiderman, & Antoni (2009)	Cross-sectional	IPQ-R: Partially - cause items were adapted to suit the sample (though not using a formal factor analysis)	Cause (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5)	Pearson's Correlation	None	Meta-Analysis
Van Der Kloot, Kobayashi, Yamaoka, Inoue, Nortier, & Kaptein (2014)	Longitudinal	B-IPQ: Yes	Identity (1), Timeline - Acute/Chronic (1), Consequences (1), Personal Control (1), Treatment Control (1), Illness Coherence (1), Emotional Representations (2)	Pearson's Correlation	- Country - Cancer Type	Meta-Analysis
Wu, Mohamed, Winkel, & Diefenbach (2013)	Longitudinal	IPQ-R: Yes - 'prostate cancer' substituted for 'illness'	Timeline - Acute/Chronic (6), Treatment Control (5)	Bivariate Correlation	- Age - Sexual Function	Meta-Analysis
Živkovic, Buljan, Blajic, & Situm (2008)	Cross-sectional	B-IPQ: Yes	Identity (1), <b>Cause (1), Timeline - Acute/Chronic (1), Consequences (1), Personal Control (1), Treatment Control (1), Illness Coherence (1),</b> Emotional Representations (2)	Pearson's Correlation	None	Meta-Analysis

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*Note:* \*Dimensions that appear are in bold were assessed by authors but not reported by authors for some outcomes

## Appendix 2.11 Meta-analysis forest plots between illness representations and coping behaviours and illness representations and illness outcomes (Study 1)

Note: See Pages 255-256 for the key to each study code.

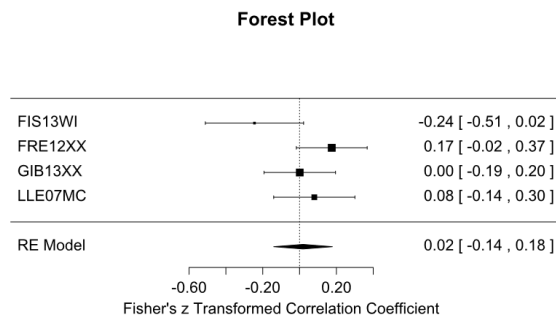


Figure 1. Cognitive Reappraisal and Identity

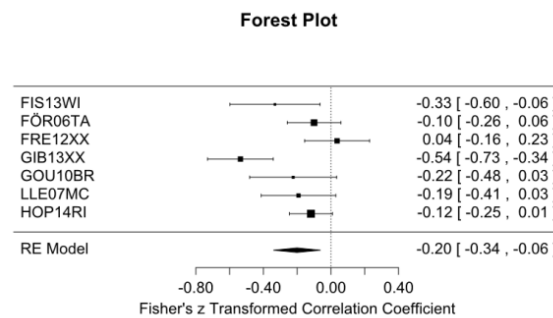


Figure 2. Cognitive Reappraisal and Acute/Chronic Timeline

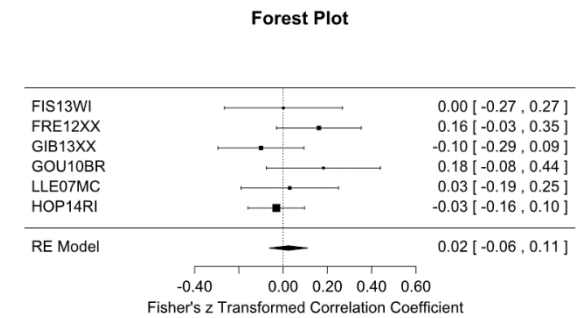


Figure 3. Cognitive Reappraisal and Cyclical Timeline

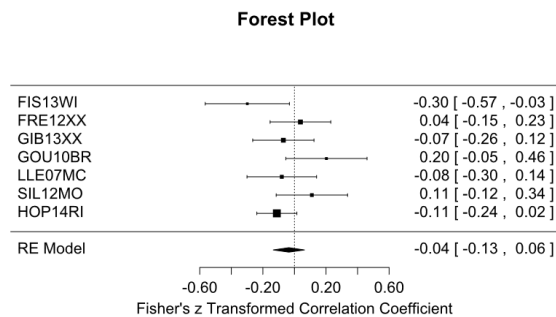


Figure 4. Cognitive Reappraisal and Consequences

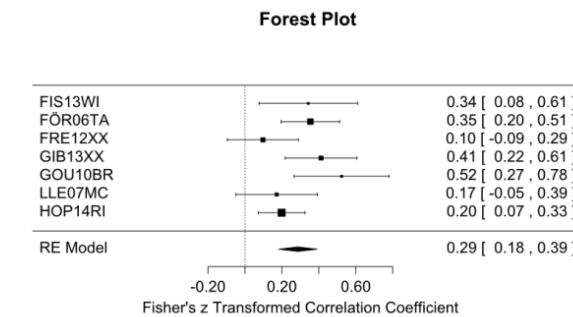


Figure 5. Cognitive Reappraisal and Personal Control

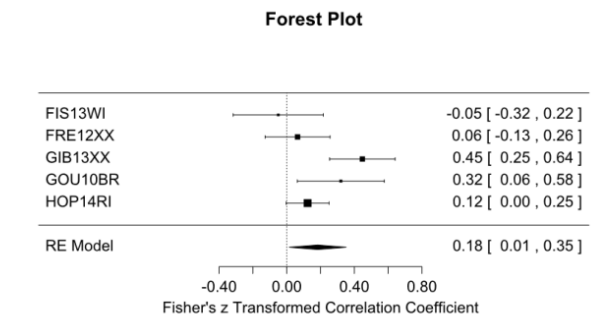


Figure 6. Cognitive Reappraisal and Treatment Control

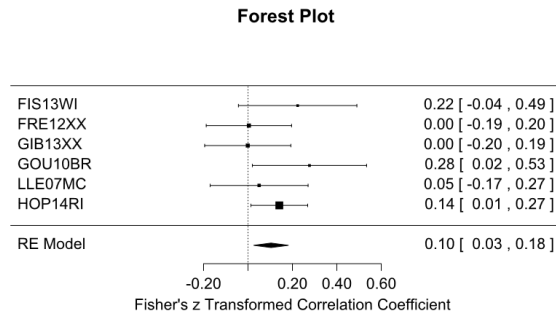


Figure 7. Cognitive Reappraisal and Illness Coherence

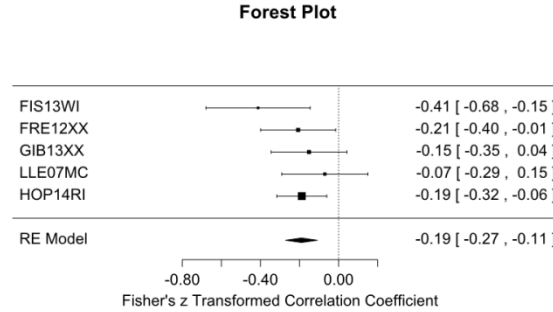


Figure 8. Cognitive Reappraisal and Emotional Representations

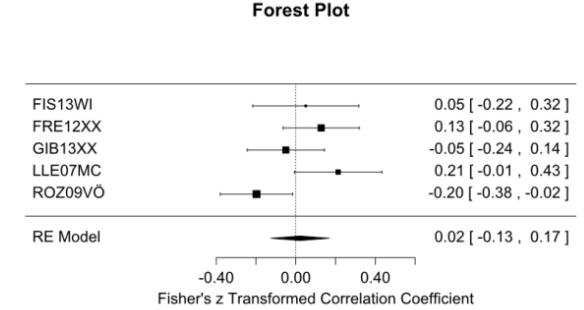


Figure 9. Avoidance/Denial and Identity

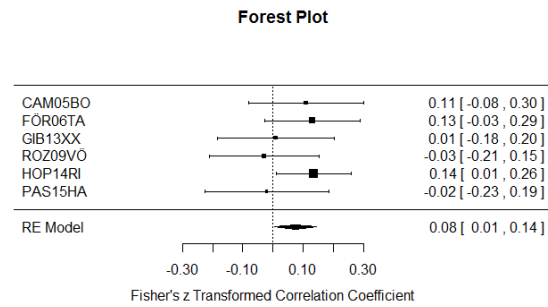


Figure 10. Avoidance/Denial and Cause

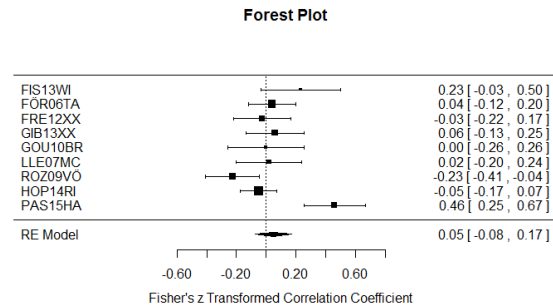


Figure 11. Avoidance/Denial and Acute/Chronic Timeline

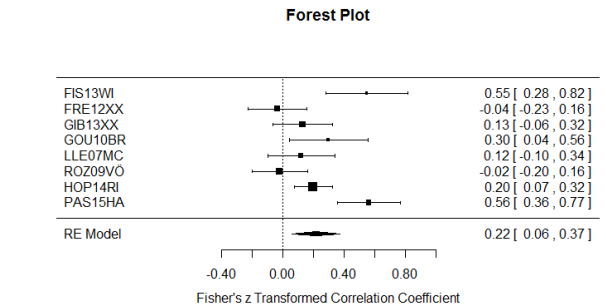


Figure 12. Avoidance/Denial and Cyclical Timeline

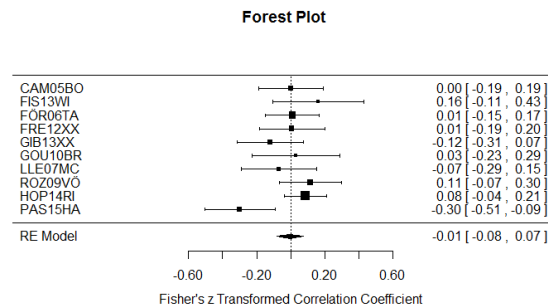


Figure 13. Avoidance/Denial and Consequences

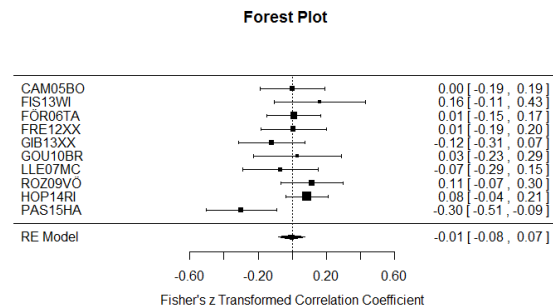


Figure 14. Avoidance/Denial and Personal Control

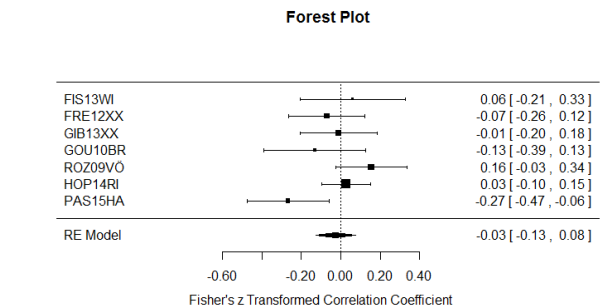


Figure 15. Avoidance/Denial and Treatment Control



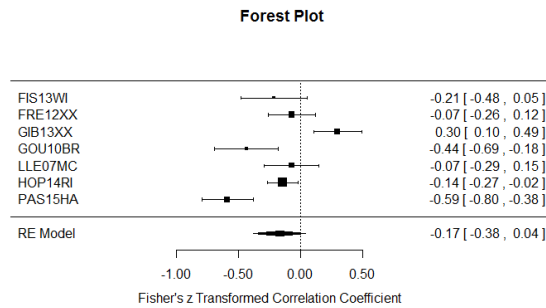


Figure 16. Avoidance/Denial and Illness Coherence

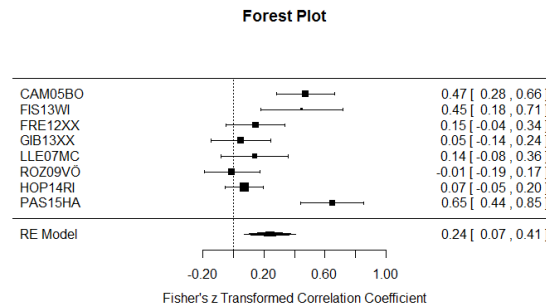


Figure 17. Avoidance/Denial and Emotional Representations

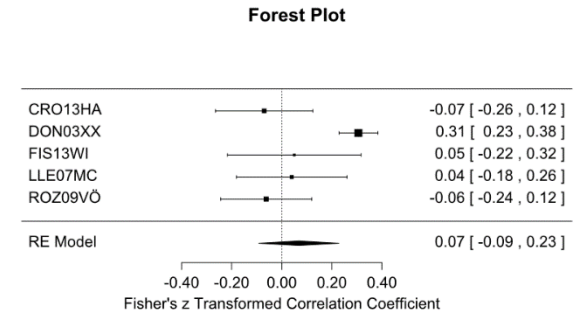


Figure 18. Problem-Focused Coping (Generic) and Identity

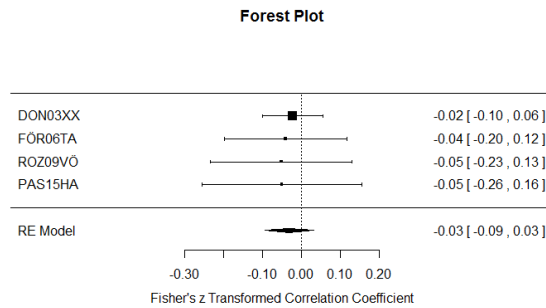


Figure 19. Problem-Focused Coping (Generic) and Cause

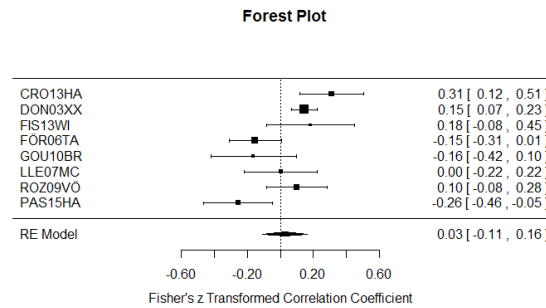


Figure 20. Problem-Focused Coping (Generic) and Acute/Chronic Timeline

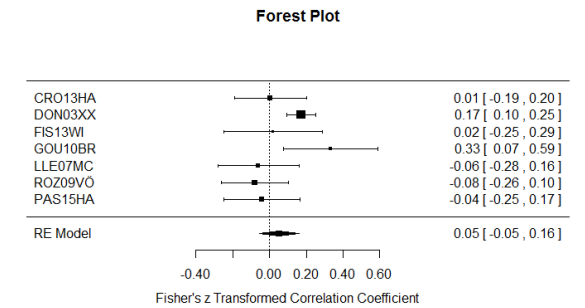


Figure 21. Problem-Focused Coping (Generic) and Cyclical Timeline

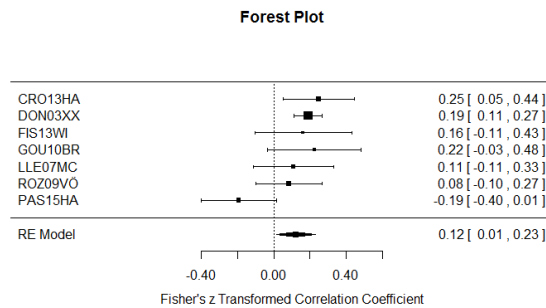


Figure 22. Problem-Focused Coping (Generic) and Consequences

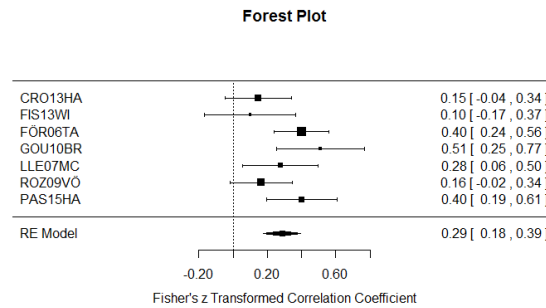


Figure 23. Problem-Focused Coping (Generic) and Personal Control

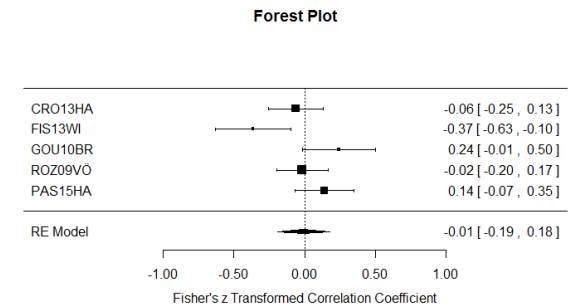


Figure 24. Problem-Focused Coping (Generic) and Treatment Control

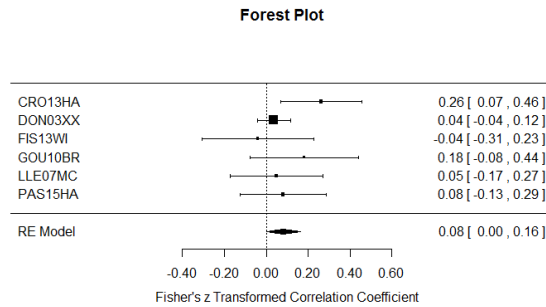


Figure 25. Problem-Focused Coping (Generic) and Illness Coherence

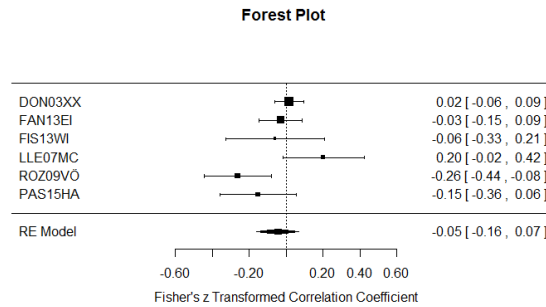


Figure 26. Problem-Focused Coping (Generic) and Emotional Representations

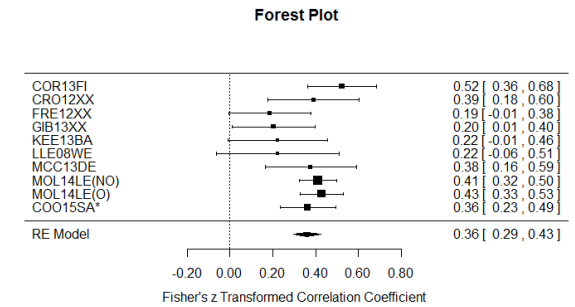


Figure 27. Anxiety and Identity

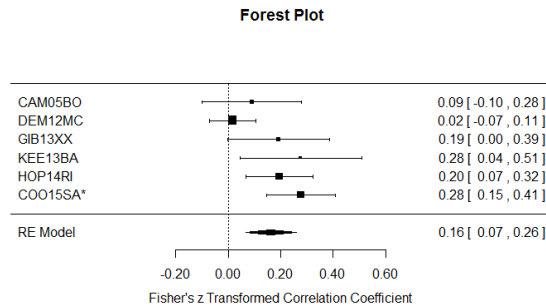


Figure 28. Anxiety and Cause

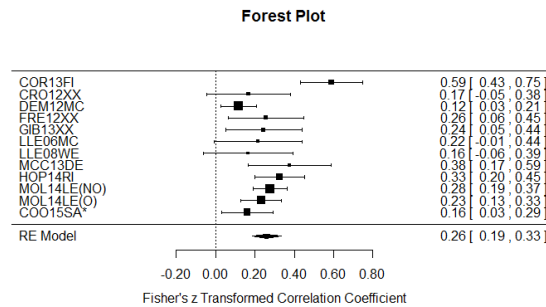


Figure 29. Anxiety and Acute/Chronic Timeline

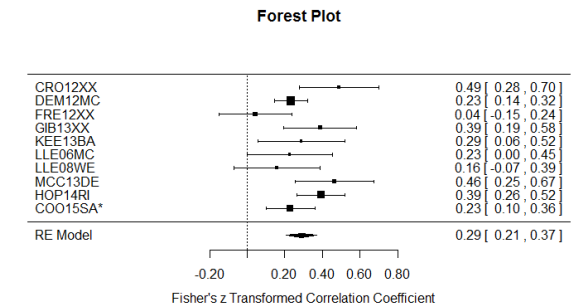


Figure 30. Anxiety and Cyclical Timeline

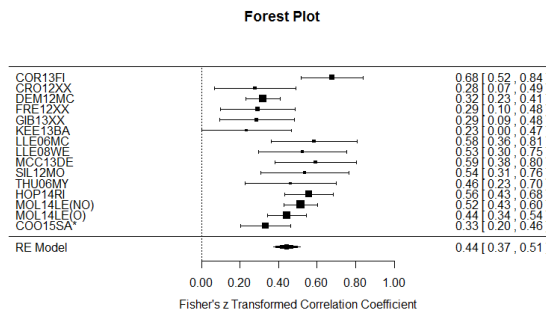


Figure 31. Anxiety and Consequences

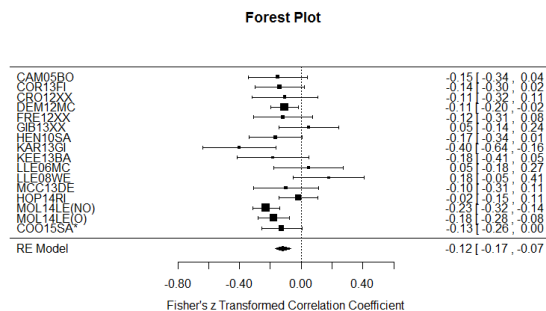


Figure 32. Anxiety and Personal Control

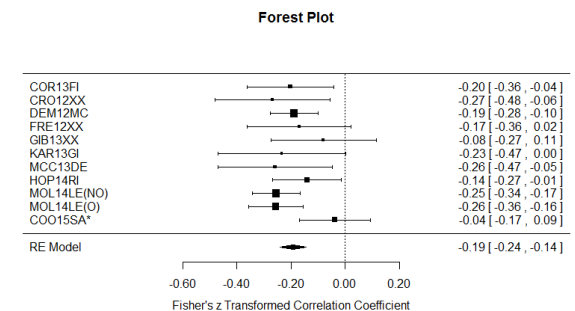


Figure 33. Anxiety and Treatment Control

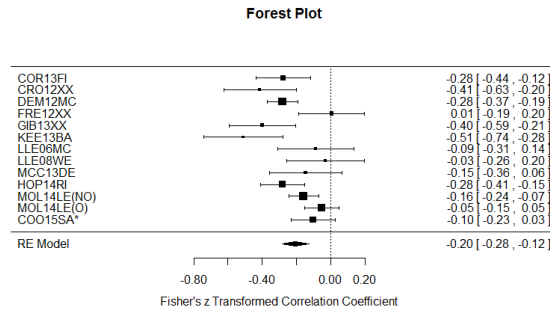


Figure 34. Anxiety and Illness Coherence Emotional Representations

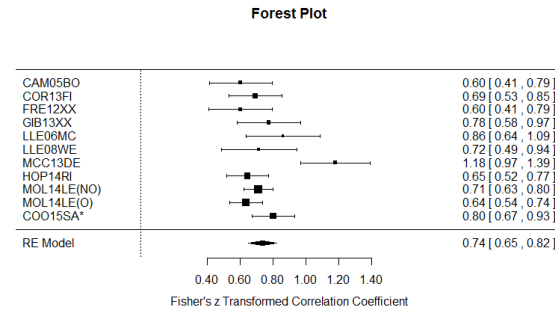


Figure 35. Anxiety and Emotional Representations

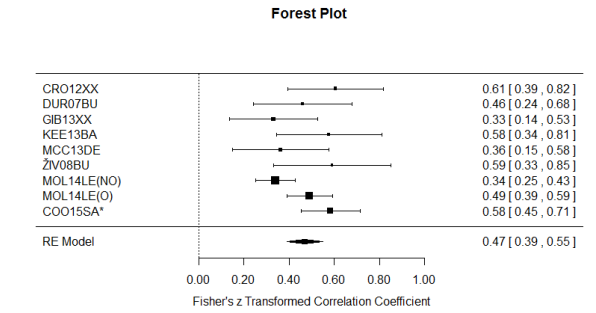


Figure 36. Depression and Identity

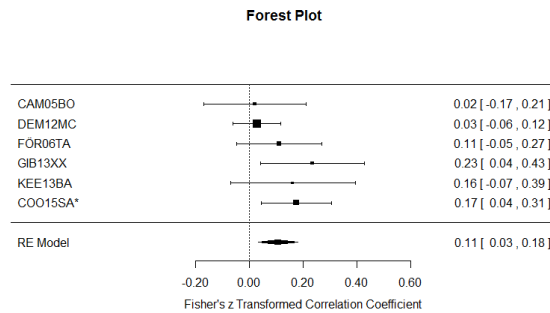


Figure 37. Depression and Cause

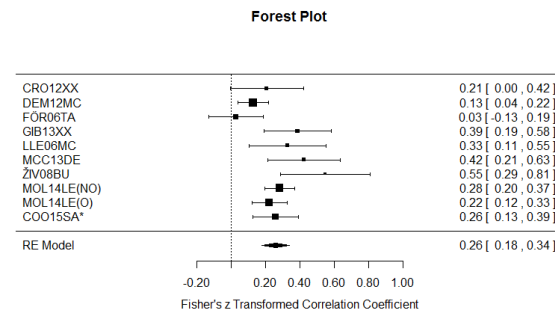


Figure 38. Depression and Acute/Chronic Timeline

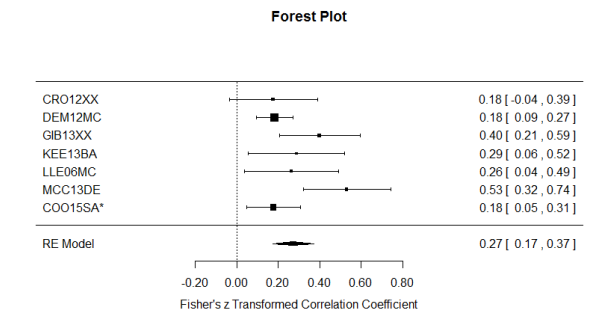


Figure 39. Depression and Cyclical Timeline

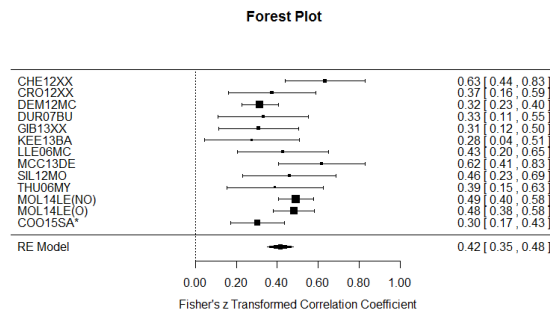


Figure 40. Depression and Consequences

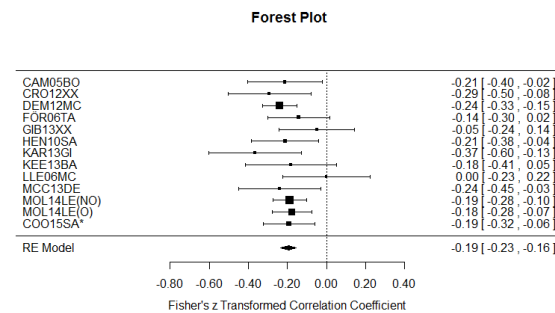


Figure 41. Depression and Personal Control

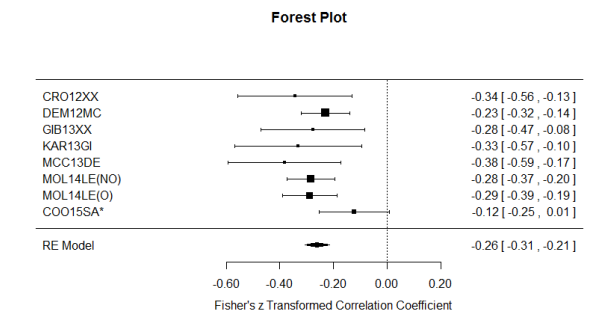


Figure 42. Depression and Treatment Control

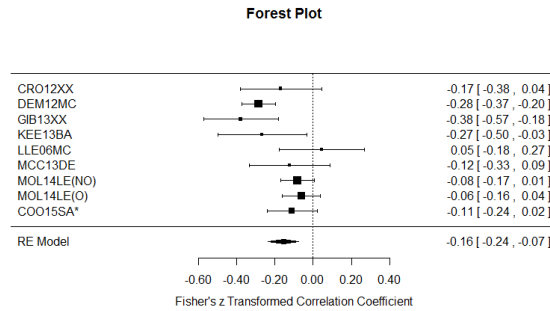


Figure 43. Depression and Illness Coherence

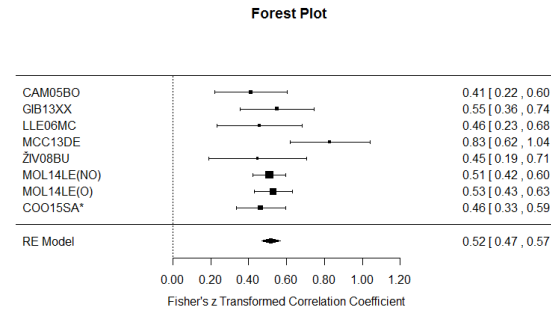


Figure 44. Depression and Emotional Representations

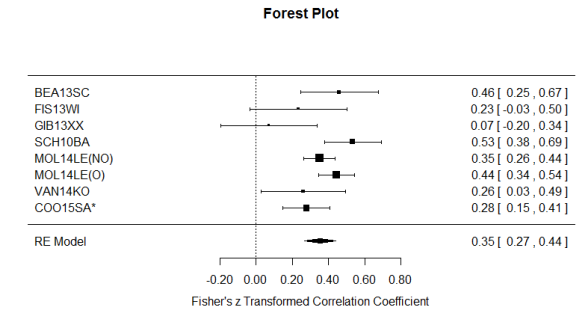


Figure 45. Psychological Distress and Identity

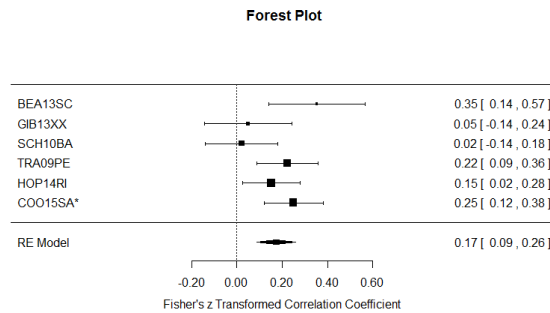


Figure 46. Psychological Distress and Cause

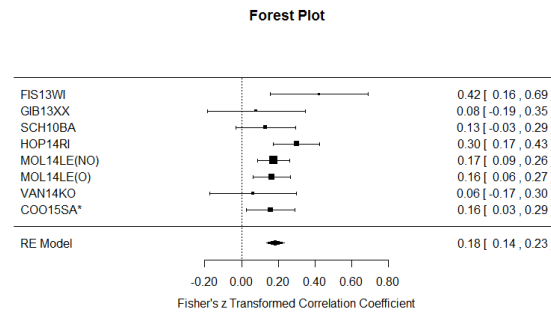


Figure 47. Psychological Distress and Acute/Chronic Timeline

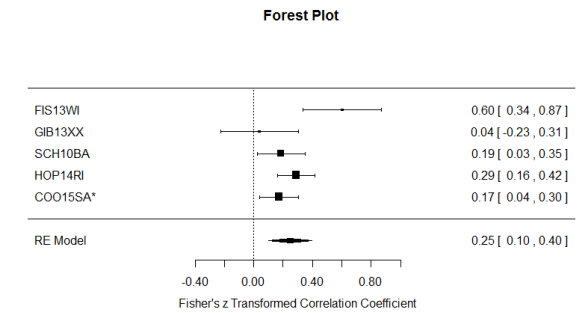


Figure 48. Psychological Distress and Cyclical Timeline

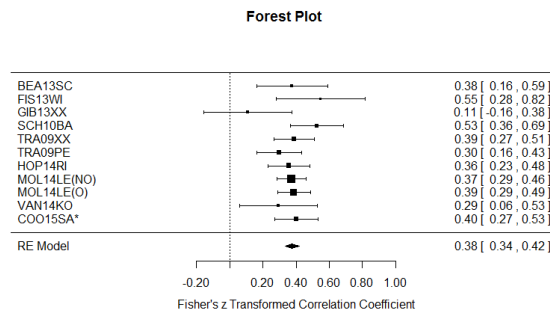


Figure 49. Psychological Distress and Consequences

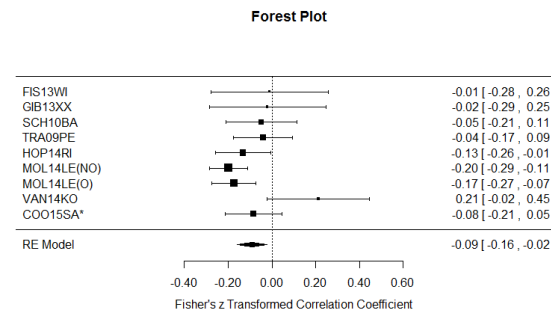


Figure 50. Psychological Distress and Personal Control

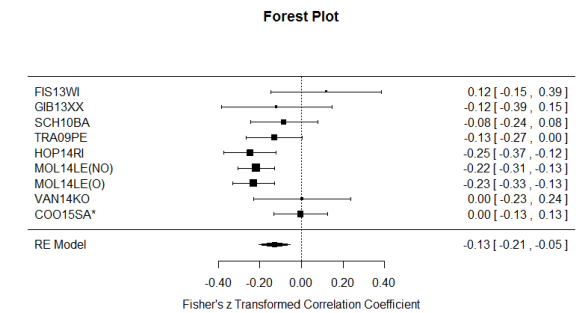


Figure 51. Psychological Distress and Treatment Control

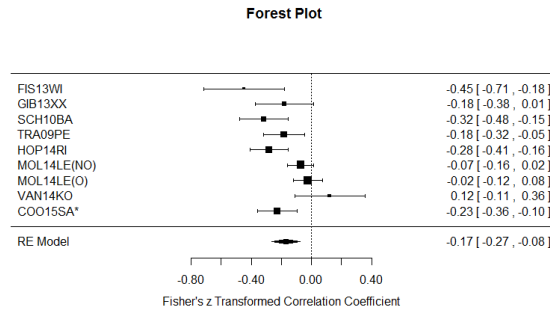


Figure 52. Psychological Distress and Illness Coherence

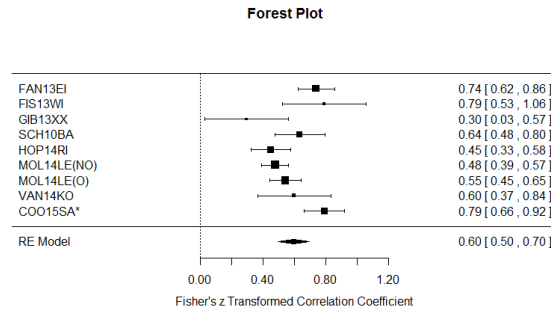


Figure 53. Psychological Distress and Emotional Representations

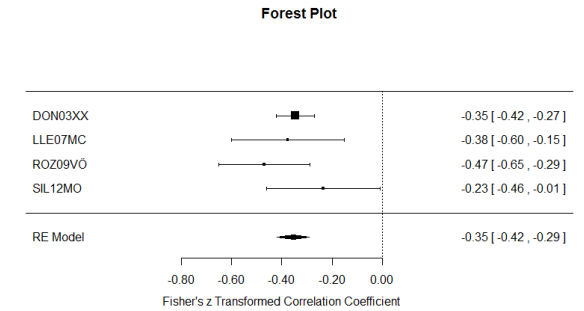


Figure 54. Psychological Well-Being and Consequences

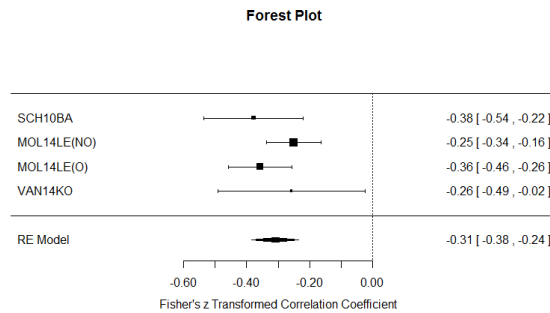


Figure 55. Role Functioning and Identity

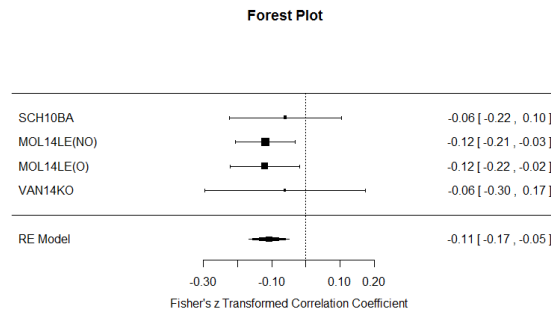


Figure 56. Role Functioning and Acute/Chronic Timeline

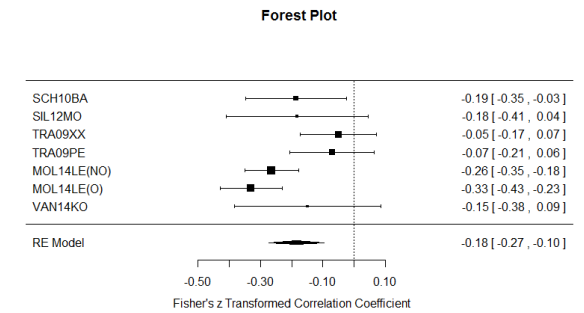


Figure 57. Role Functioning and Consequences

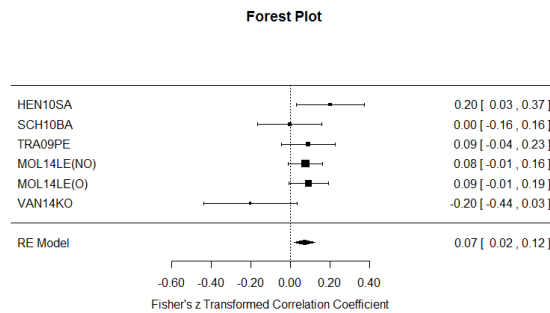


Figure 58. Role Functioning and Personal Control

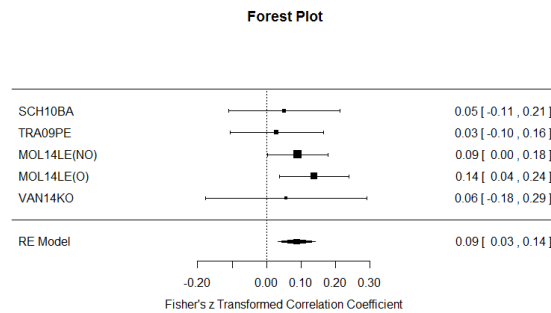


Figure 59. Role Functioning and Treatment Control

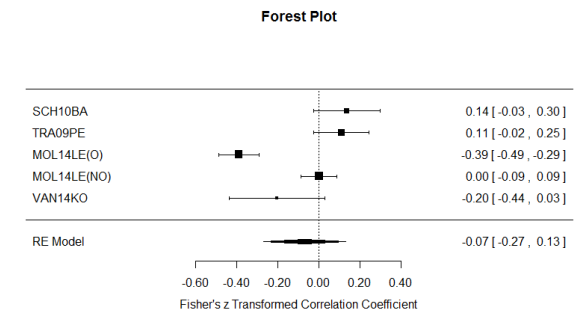


Figure 60. Role Functioning and Illness Coherence

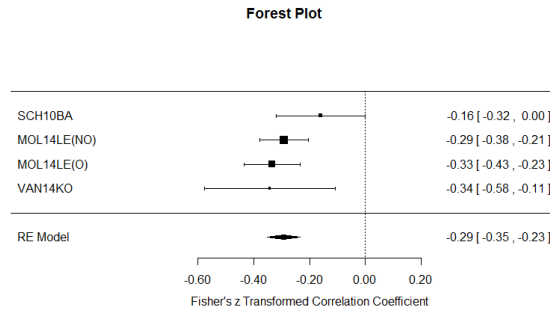


Figure 61. Role Functioning and Emotional Representations

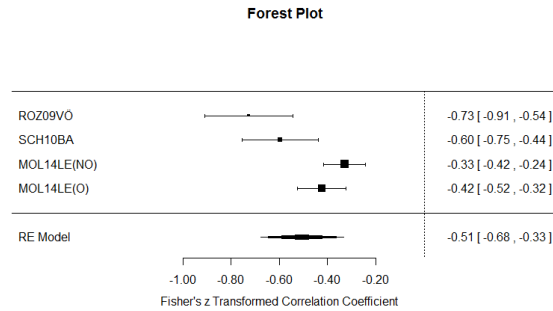


Figure 62. Physical Functioning and Identity

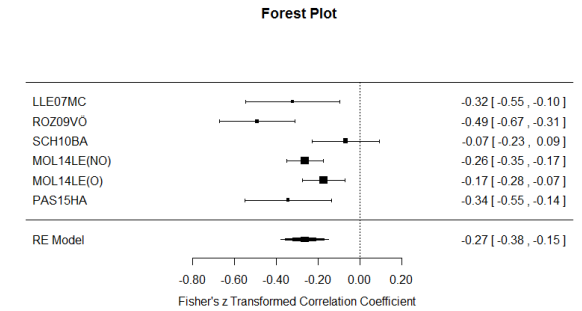


Figure 63. Physical Functioning and Acute/Chronic Timeline

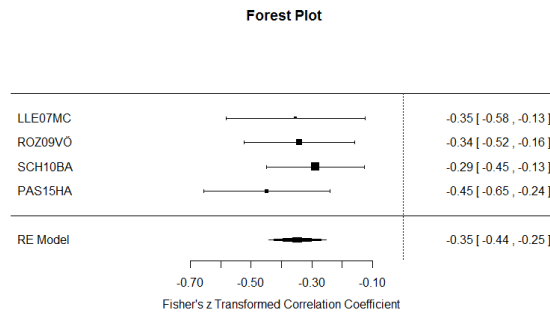


Figure 64. Physical Functioning and Cyclical Timeline

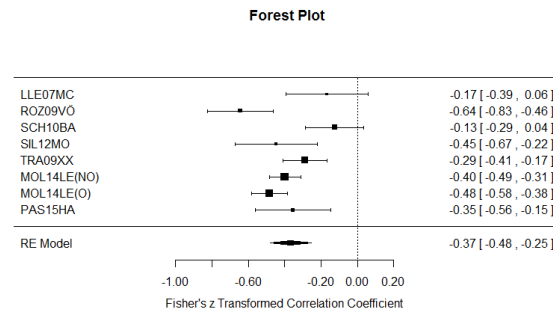


Figure 65. Physical Functioning and Consequences

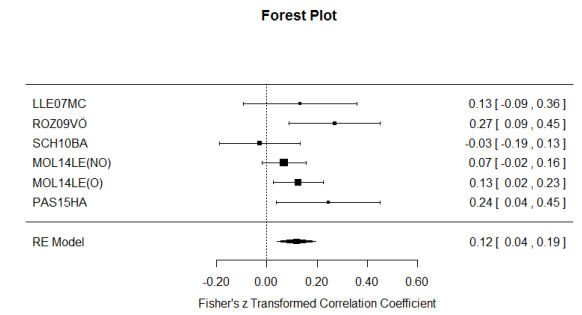


Figure 66. Physical Functioning and Personal Control

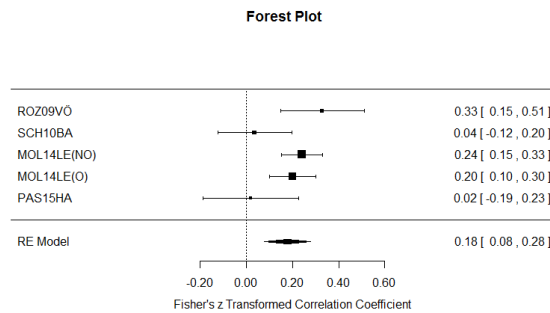


Figure 67. Physical Functioning and Treatment Control

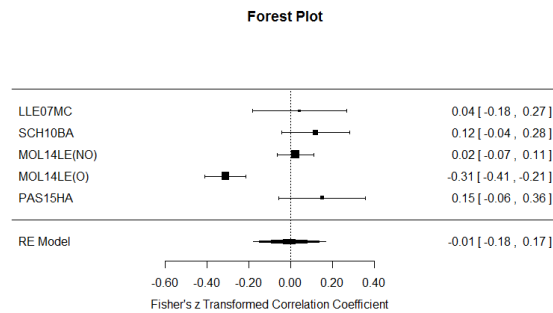


Figure 68. Physical Functioning and Illness Coherence

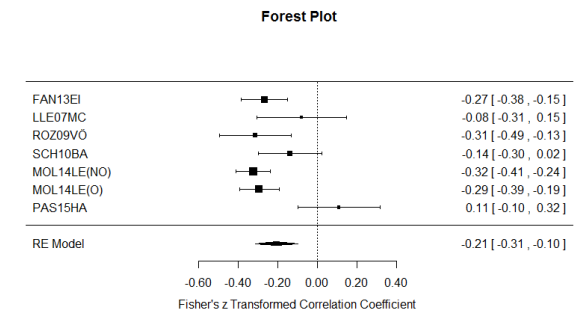


Figure 69. Physical Functioning and Emotional Representations

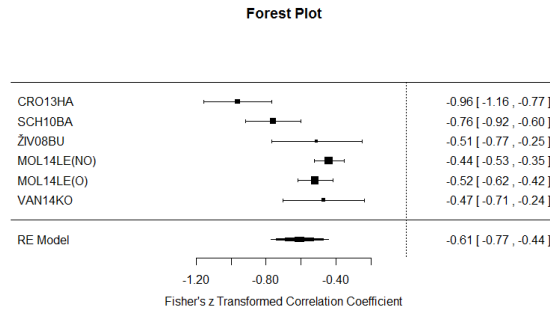


Figure 70. Quality of Life and Identity

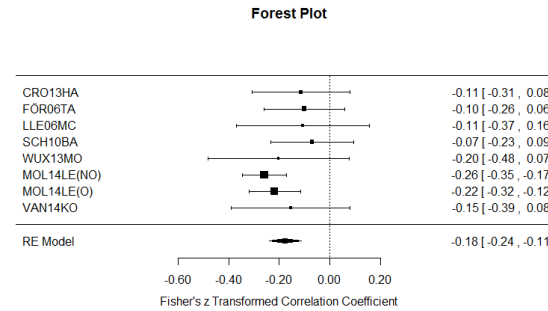


Figure 71. Quality of Life and Acute/Chronic Timeline

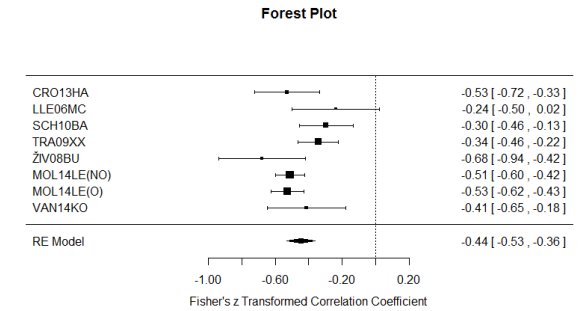


Figure 72. Quality of Life and Consequences

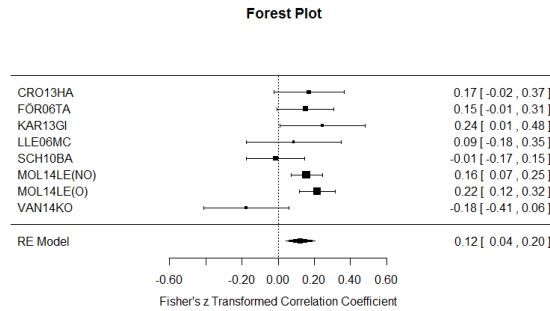


Figure 73. Quality of Life and Personal Control

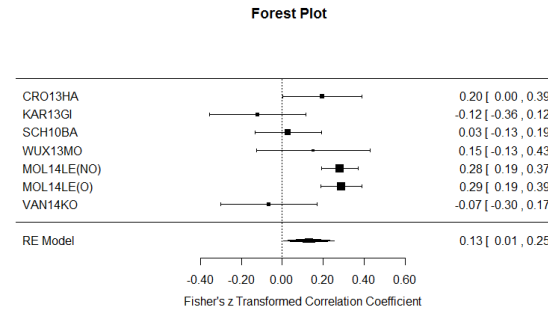


Figure 74. Quality of Life and Treatment Control

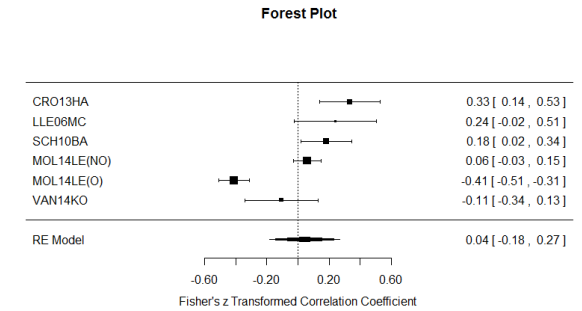


Figure 75. Quality of Life and Illness Coherence

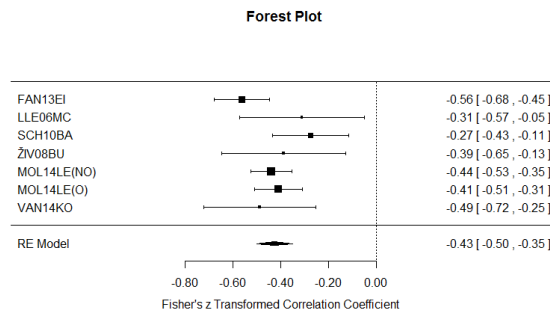


Figure 76. Quality of Life and Emotional Representations

### Study codes with associated authors and dates

Study Code	Authors (Date)
BEA13SC	Beatty and Scott (2013)
CAM05BO	Cameron, Booth, Schlatter, Ziginskis, Harman, & Benson (2005)
CHE12XX	Chen (2013)
COO13HA	Cooper, Hankins, Rixon, Eaton, & Grunfeld (2013)
COO15SA	Cook, Salman, Dunn, Holcombe, Cornford, & Fisher (2015)
COO15SA*	Cook, Salman, Dunn, Holcombe, Cornford, & Fisher (2015)
COR13FI	Corter, Findlay, Broom, Porter, & Petrie (2013)
COS11LU	Costanzo, Lutgendorf, & Roeder (2011)
CRO12XX	Croom (2012)
CRO13HA	Croom, Hamann, Kehoe, Paulk, & Wiebe (2013)
DEM12MC	Dempster, McCorry, Brennan, Donnelly, Murray, & Johnston (2012)
DEM11MC	Dempster, McCorry, Brennan, Donnelly, Murray, & Johnston (2011)
DON03XX	Donovan (2003)
DUR07BU	Duric, Butow, Sharpe, Boyle, Beith, Wilcken, Heritier, Coates, Simes, & Stockler (2007)
FAN13EI	Fan, Eiser, Ho, & Lin (2013)
FIS13WI	Fischer, Wiesenhaan, Heijer, Kleijn, Nortier, & Kaptein (2013)
FÖR06TA	Förster & Taubert (2006)
FOS14BR	Foster, Breckons, Cotterell, Barbosa, Calman, Corner, Fenlon, Foster, Grimmett, Richardson, & Smith (2015)
FRE12XX	Freeman-Gibb (2012)
GIA10MA	Giannousi, Manaras, Georgoulas, & Samonis (2010)
GIB13XX	Gibbons (2013)
GOU10BR	Gould, Brown, & Bramwell (2010)
GRA06MY	Grande, Myers, & Sutton (2006)
GRA14AR	Grande, Arnott, Brundle, & Pilling (2014)
GRA14HA	Gray, Hall, Browne, Johnston, Lee, Macleod, Mitchell, Samuel, & Campbell (2014)
GRA11HA	Gray, Hall, Browne, Macleod, Lee, Johnston, Wyke, Samuel, Weller, & Campbell (2011)
GRE14ST	Green, Steinnagel, Morris, & Laakso (2014)
HEN10SA	Henselmans, Sanderman, Helgeson, de Vries, Smink, & Ranchor (2010)
HOP14RI	Hopman & Rijken (2014)
ISK14DE	Iskandarsyah, de Klerk, Suardi, Sadarjoen, & Passchier (2014)



JØR09FR	Jørgensen, Frederiksen, Boesen, Elsass, & Johansen (2009)
KAR13GI	Karademas & Giannousi (2013)
KEE13BA	Keeling, Bambrough, & Simpson (2013)
LAN14MC	Landers, McCarthy, Livingstone, & Savage (2014)
LLE06MC	Llewellyn, McGurk, & Weinman (2006)
LLE07MC	Llewellyn, McGurk, & Weinman (2007)
LLE07MC*	Llewellyn, McGurk, & Weinman (2007)
LLE08WE	Llewellyn, Weinman, McGurk, & Humphris (2008)
MCC13DE	McCorry, Dempster, Quinn, Hogg, Newell, Moore, Kelly, & Kirk (2013)
MIC13VA	Mičkevičienė, Vanagas, Jievalta, & Ulys, (2013)
MIL05PU	Millar, Purushotham, McLatchie, George, & Murray (2005)
MOL14LE(NO)	Mols, Lemmens, Bosscha, van den Broek, & Thong (2014)
– No Ostomy	
MOL14LE(O)	Mols, Lemmens, Bosscha, van den Broek, & Thong (2014)
– Ostomy	
PAS15HA	Paschali, Hadjulis, Papadimitriou, & Karademas (2015)
ROZ09VÖ	Rozema, Völlink, & Lechner (2009)
SCH10BA	Scharloo, Baatenburg de Jong, Langeveld, van Velzen-Verkaik, Doorn-op den Akker, & Kaptein (2010)
SCH05BA	Scharloo, Baatenburg de Jong, Langeveld, van Velzen-Verkaik, Doorn-op den Akker, & Kaptein (2005)
SIL12MO	Silva, Moreira, & Canavarro (2012)
THU06MY	Thune-Boyle, Myers, & Newman (2006)
TRA09XX	Traeger (2009)
TRA13PE	Traeger, Penedo, Benedict, Dahn, Lechner, Schneiderman, & Antoni (2013)
TRA09PE	Traeger, Penedo, Gonzalez, Dahn, Lechner, Schneiderman, & Antoni (2009)
VAN14KO	Van Der Kloot, Kobayashi, Yamaoka, Inoue, Nortier, & Kaptein (2014)
WUX13MO	Wu, Mohamed, Winkel, & Diefenbach (2013)
ŽIV08BU	Živkovic, Buljan, Blajic, & Situm (2008)

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**Appendix 2.12** Meta-analysis funnel plots between illness representations and coping behaviours and illness representations and illness outcomes (Study 1)

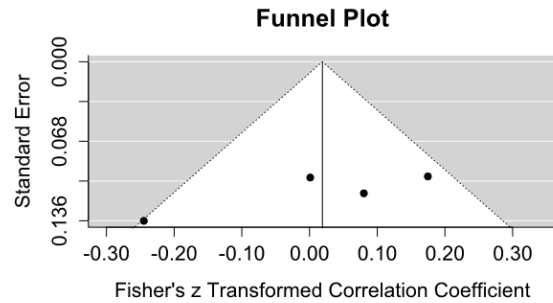


Figure 1. Cognitive Reappraisal and Identity

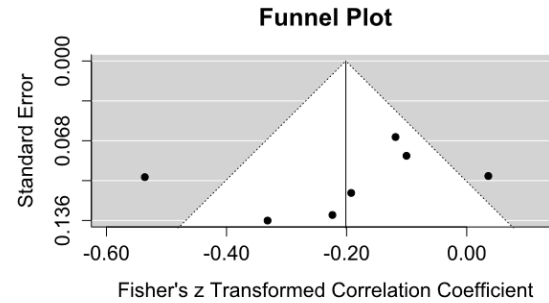


Figure 2. Cognitive Reappraisal and Acute/Chronic Timeline

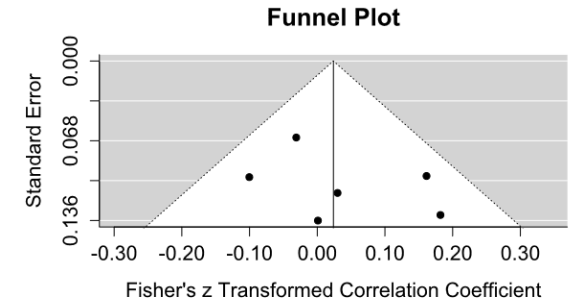


Figure 3. Cognitive Reappraisal and Cyclical Timeline

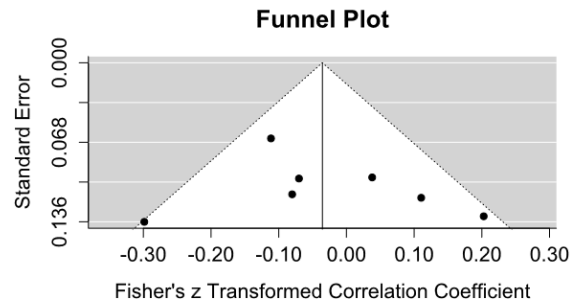


Figure 4. Cognitive Reappraisal and Consequences

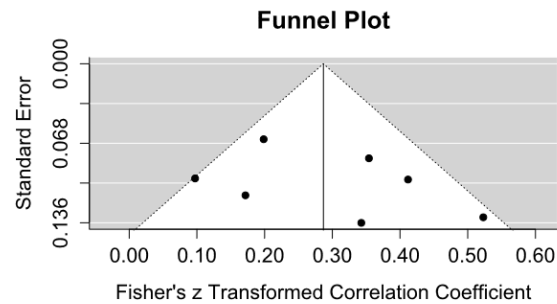


Figure 5. Cognitive Reappraisal and Personal Control

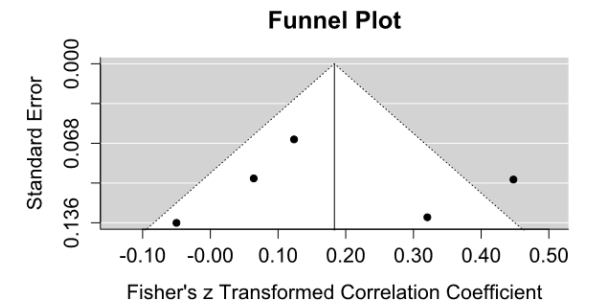


Figure 6. Cognitive Reappraisal and Treatment Control

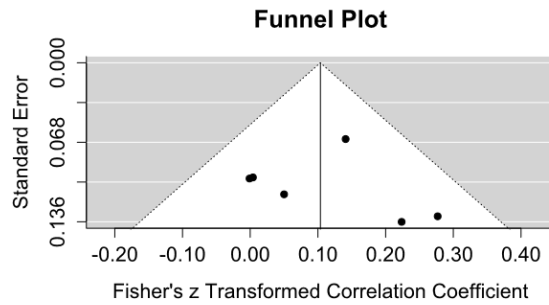


Figure 7. Cognitive Reappraisal and Illness Coherence

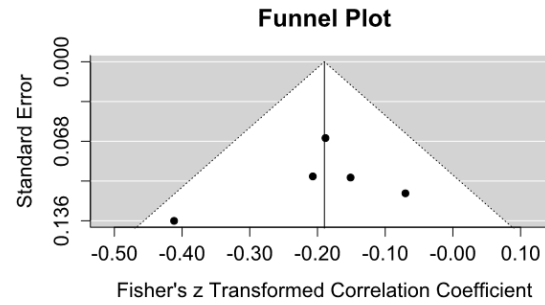


Figure 8. Cognitive Reappraisal and Emotional Representations

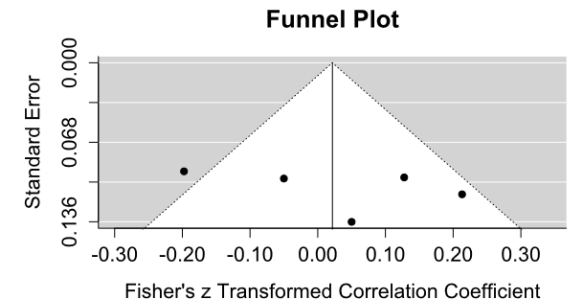


Figure 9. Avoidance/Denial and Identity

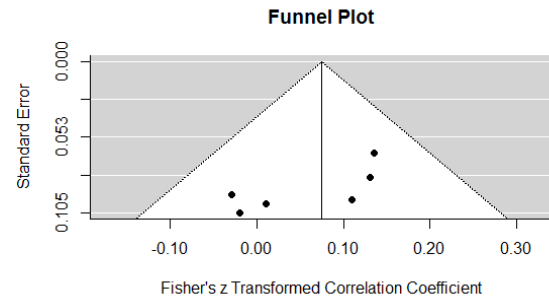


Figure 10. Avoidance/Denial and Cause

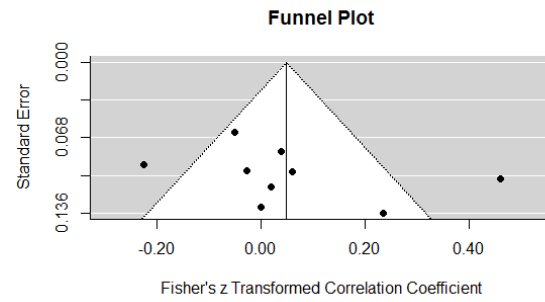


Figure 11. Avoidance/Denial and Acute/Chronic Timeline

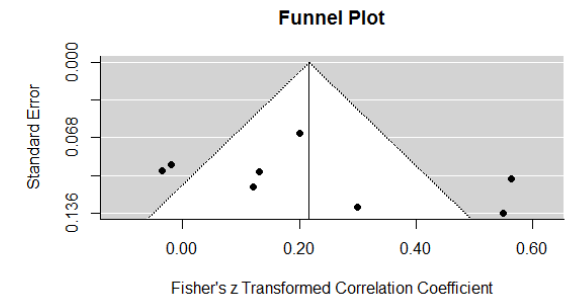


Figure 12. Avoidance/Denial and Cyclical Timeline

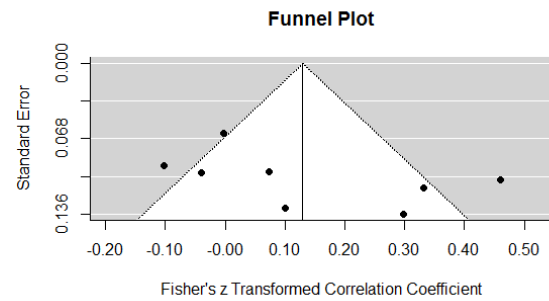


Figure 13. Avoidance/Denial and Consequences

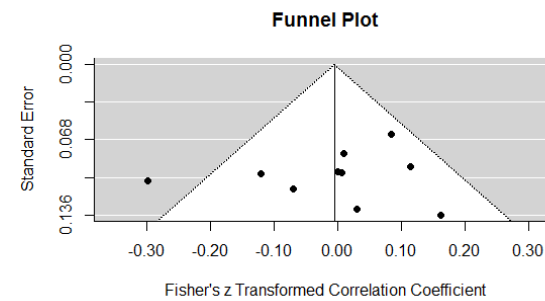


Figure 14. Avoidance/Denial and Personal Control

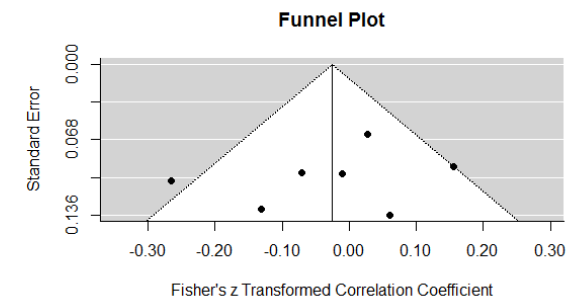


Figure 15. Avoidance/Denial and Treatment Control

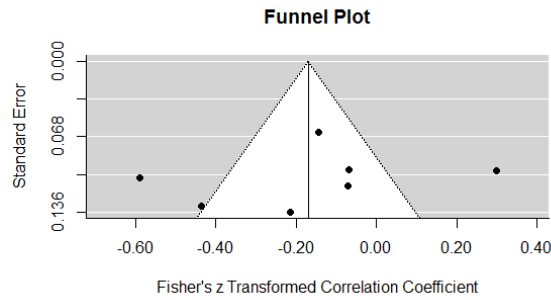


Figure 16. Avoidance/Denial and Illness Coherence

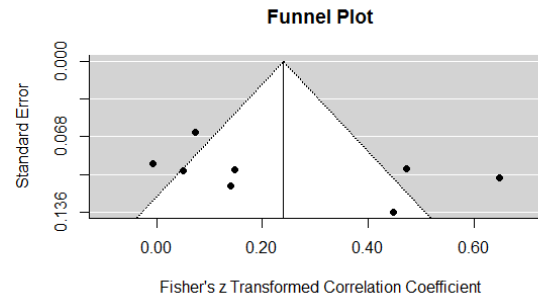


Figure 17. Avoidance/Denial and Emotional Representations

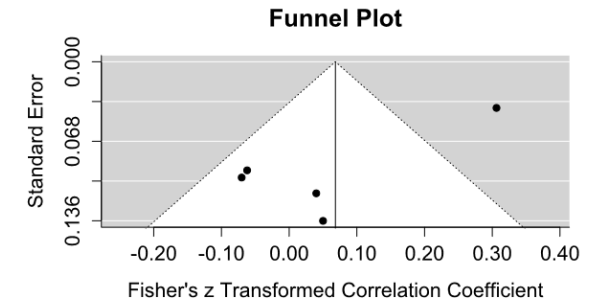


Figure 18. Problem-Focused Coping (Generic) and Identity

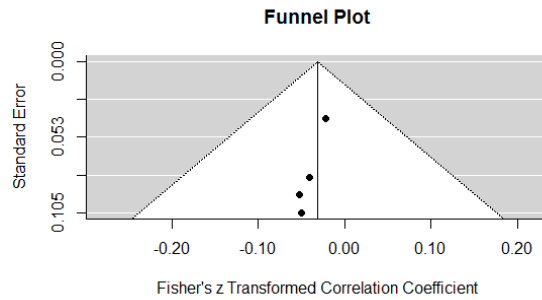


Figure 19. Problem-Focused Coping (Generic) and Cause

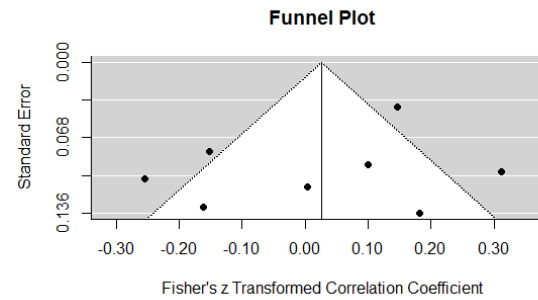


Figure 20. Problem-Focused Coping (Generic) and Acute/Chronic Timeline

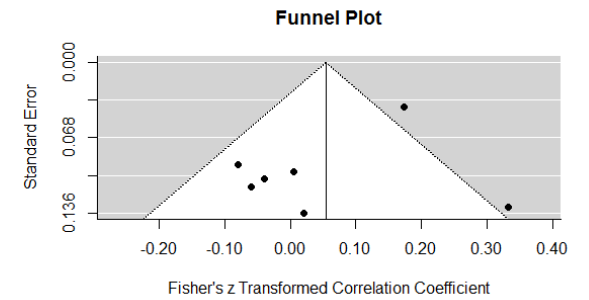


Figure 21. Problem-Focused Coping (Generic) and Cyclical Timeline

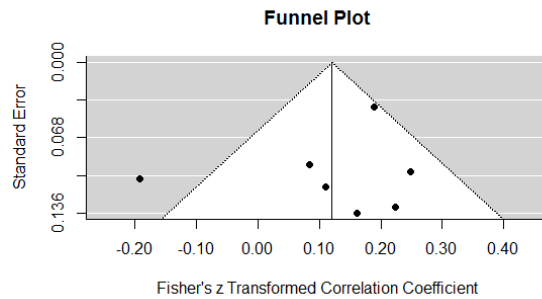


Figure 22. Problem-Focused Coping (Generic) and Consequences

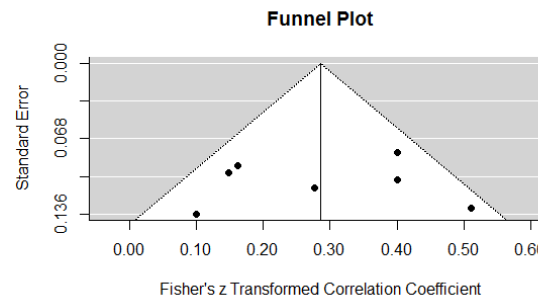


Figure 23. Problem-Focused Coping (Generic) and Personal Control

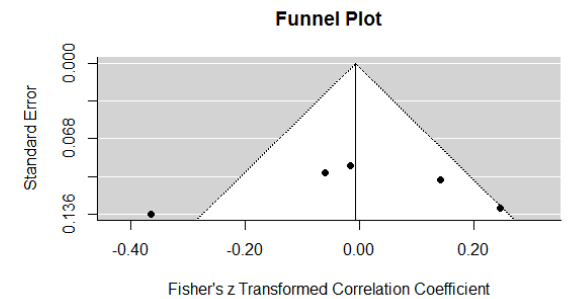


Figure 24. Problem-Focused Coping (Generic) and Treatment Control

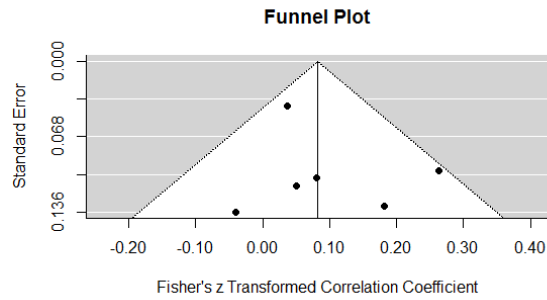


Figure 25. Problem-Focused Coping (Generic) and Illness Coherence

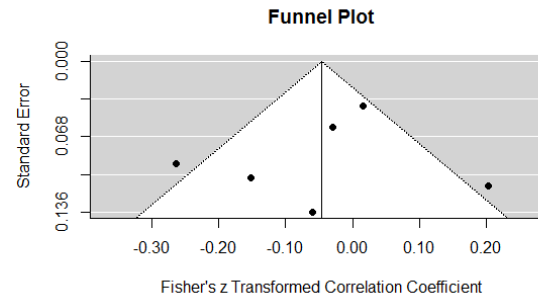


Figure 26. Problem-Focused Coping (Generic) and Emotional Representations

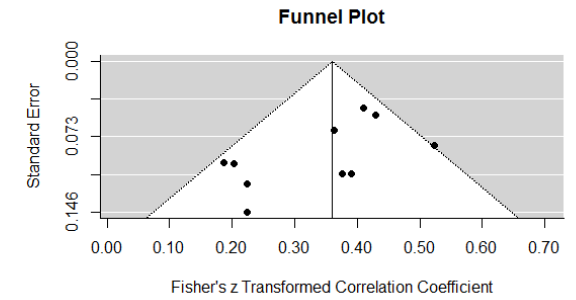


Figure 27. Anxiety and Identity

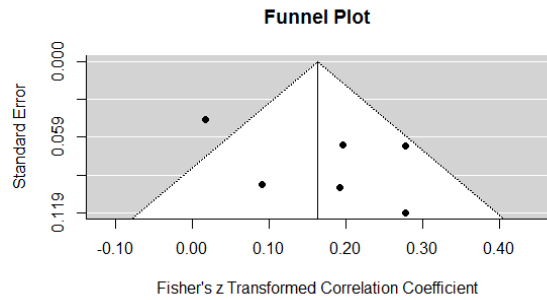


Figure 28. Anxiety and Cause

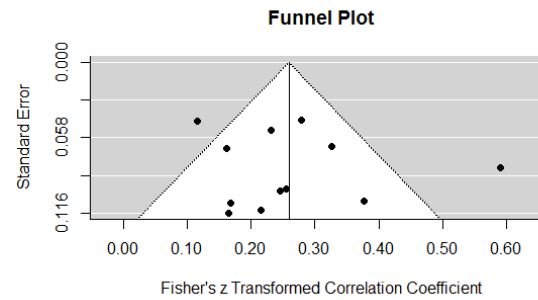


Figure 29. Anxiety and Acute/Chronic Timeline

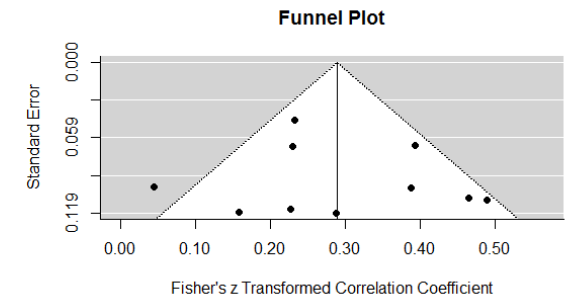


Figure 30. Anxiety and Cyclical Timeline

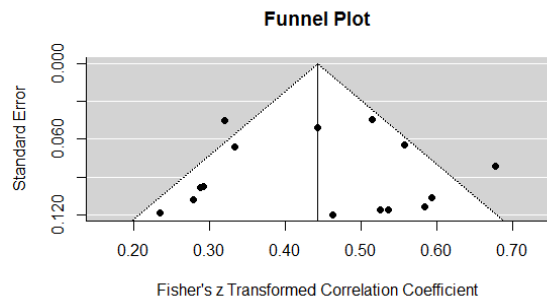


Figure 31. Anxiety and Consequences

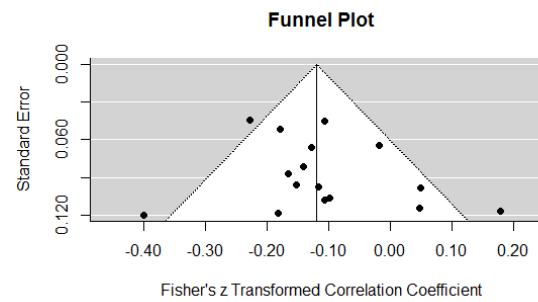


Figure 32. Anxiety and Personal Control

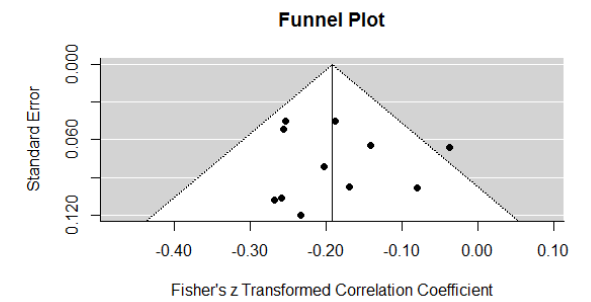


Figure 33. Anxiety and Treatment Control

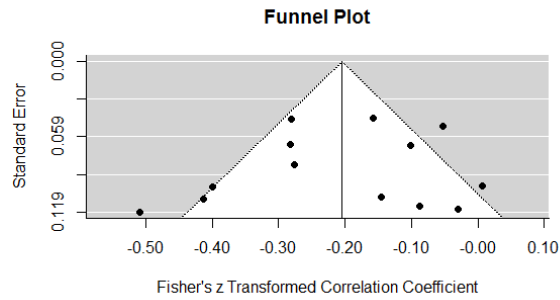


Figure 34. Anxiety and Illness Coherence

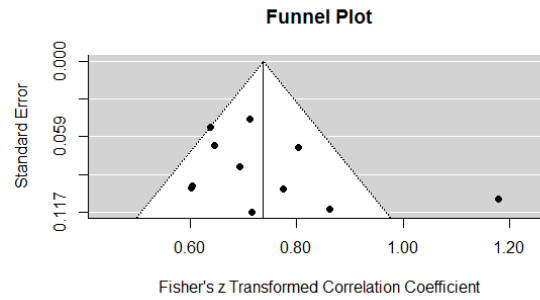


Figure 35. Anxiety and Emotional Representations

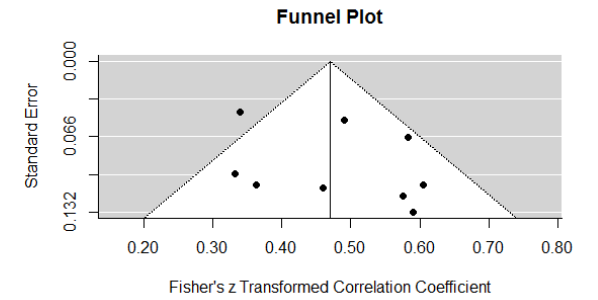


Figure 36. Depression and Identity

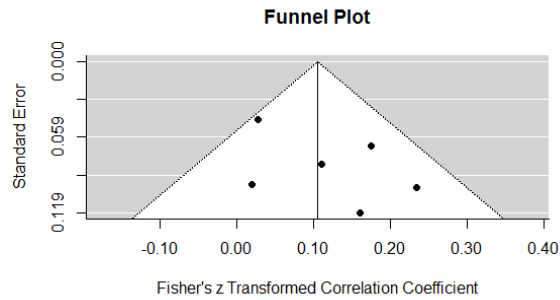


Figure 37. Depression and Cause

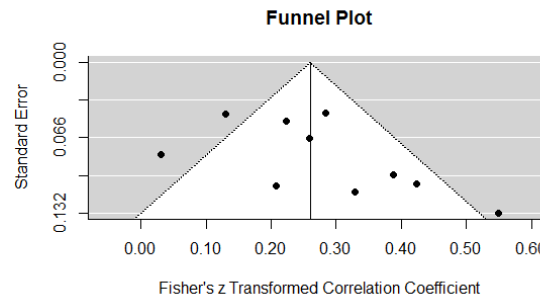


Figure 38. Depression and Acute/Chronic Timeline

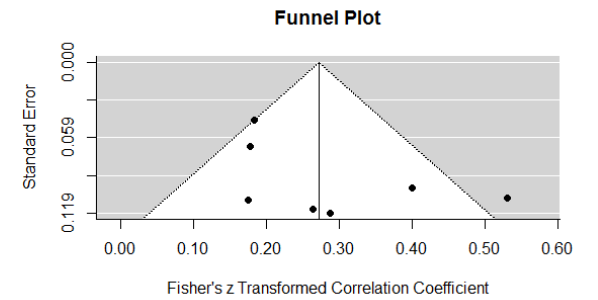


Figure 39. Depression and Cyclical Timeline

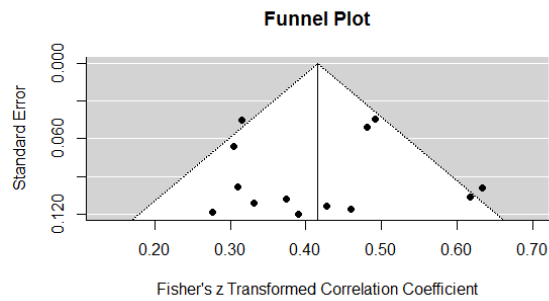


Figure 40. Depression and Consequences

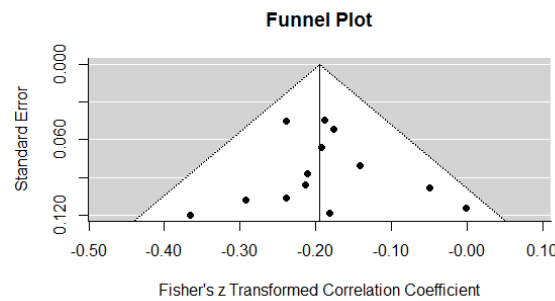


Figure 41. Depression and Personal Control

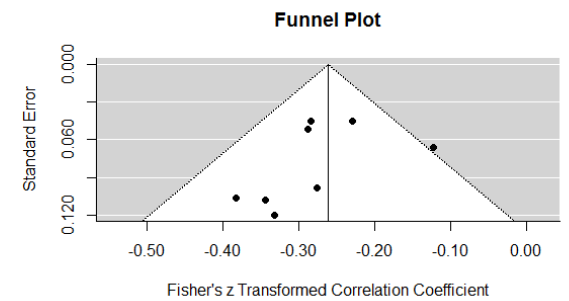


Figure 42. Depression and Treatment Control

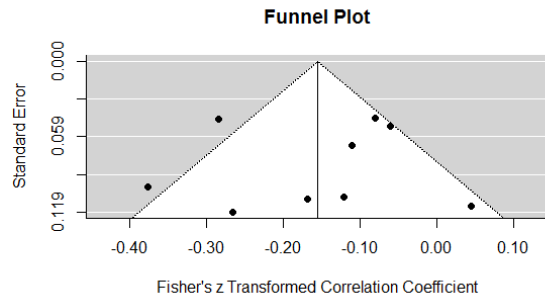


Figure 43. Depression and Illness Coherence

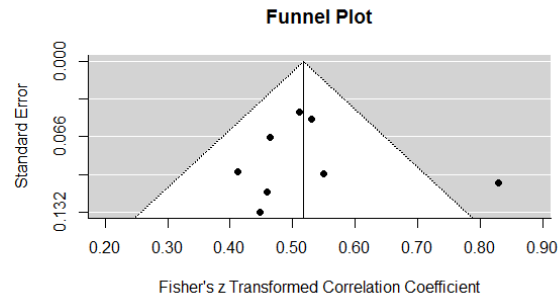


Figure 44. Depression and Emotional Representations

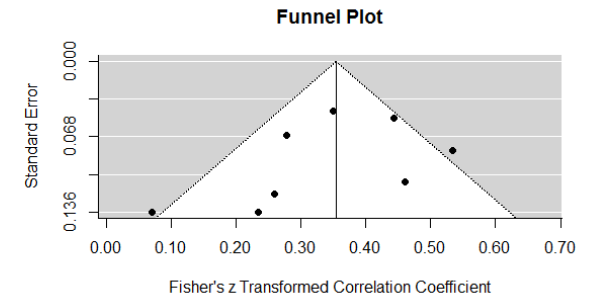


Figure 45. Psychological Distress and Identity

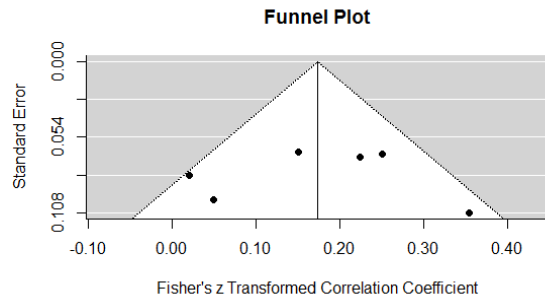


Figure 46. Psychological Distress and Cause

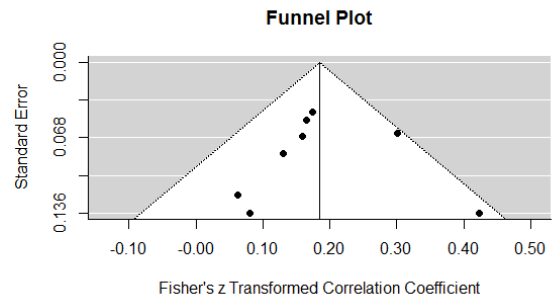


Figure 47. Psychological Distress and Acute/Chronic Timeline

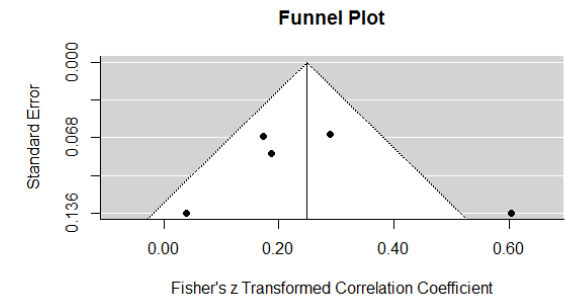


Figure 48. Psychological Distress and Cyclical Timeline

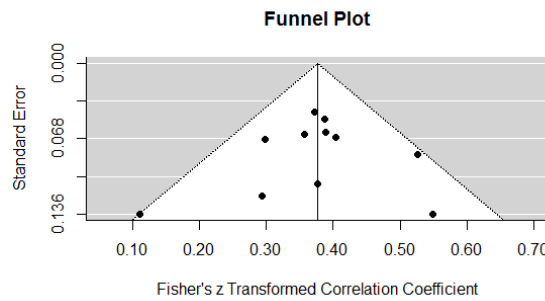


Figure 49. Psychological Distress and Consequence

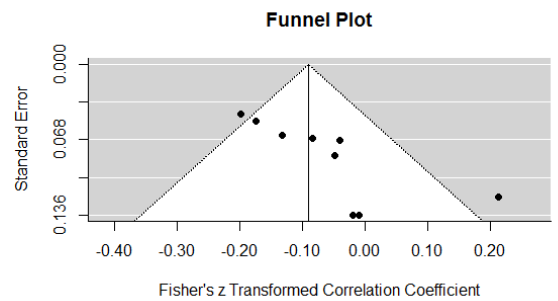


Figure 50. Psychological Distress and Personal Control

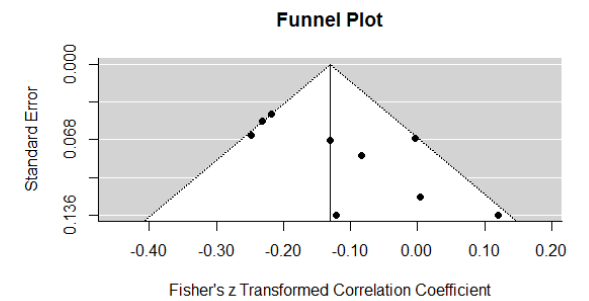


Figure 51. Psychological Distress and Treatment Control

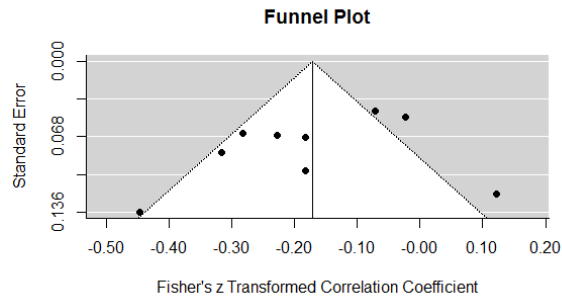


Figure 52. Psychological Distress and Illness Coherence

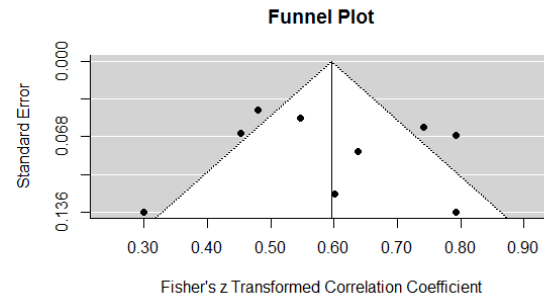


Figure 53. Psychological Distress and Emotional Representations

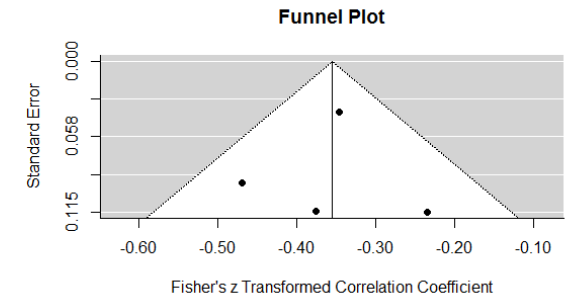


Figure 54. Psychological Well-Being and Consequences

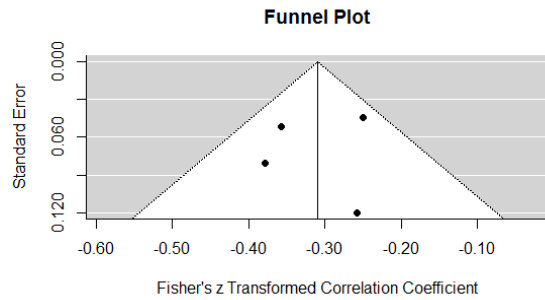


Figure 55. Role Functioning and Identity

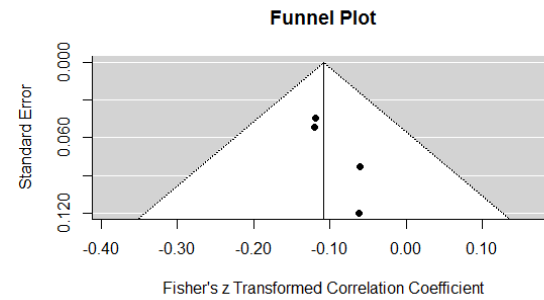


Figure 56. Role Functioning and Acute/Chronic Timeline

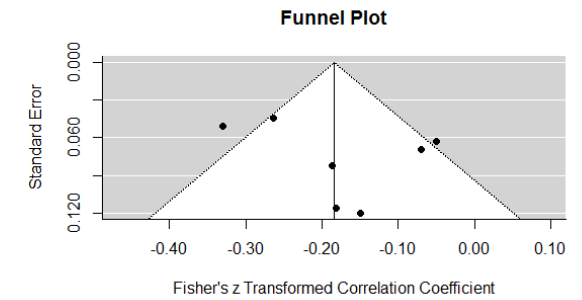


Figure 57. Role Functioning and Consequences

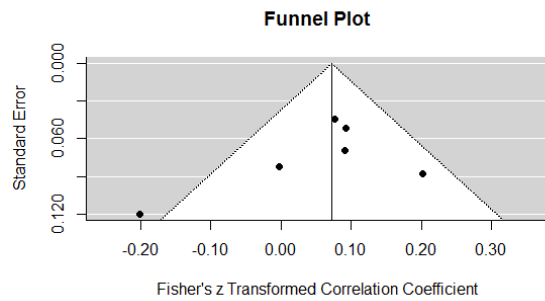


Figure 58. Role Functioning and Personal Control

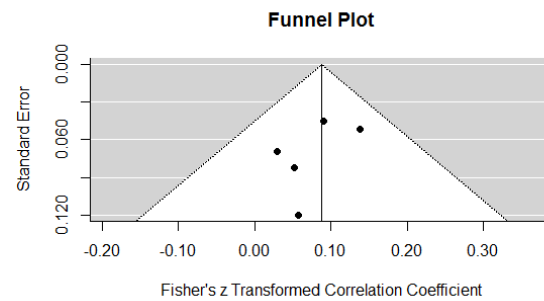


Figure 59. Role Functioning and Treatment Control

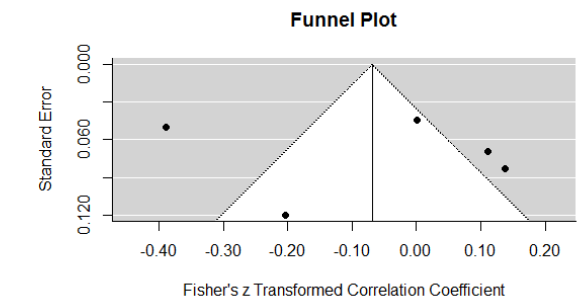


Figure 60. Role Functioning and Illness Coherence



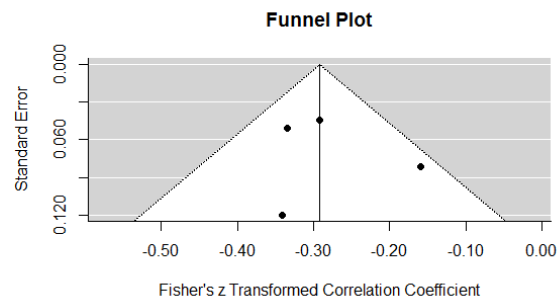


Figure 61. Role Functioning and Emotional Representations

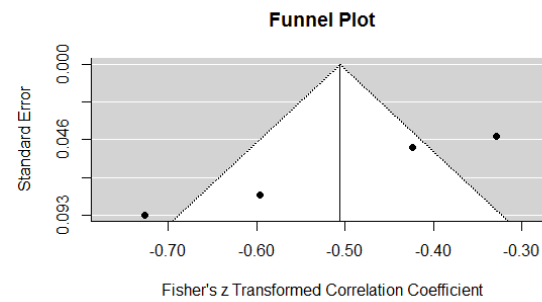


Figure 62. Physical Functioning and Identity

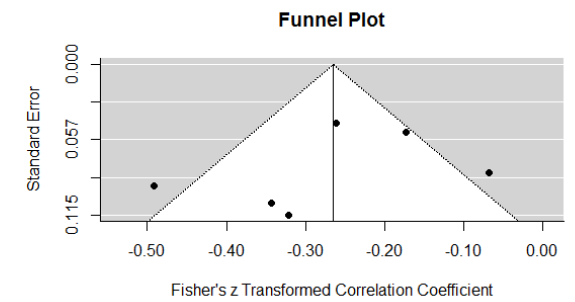


Figure 63. Physical Functioning and Acute/Chronic Timeline

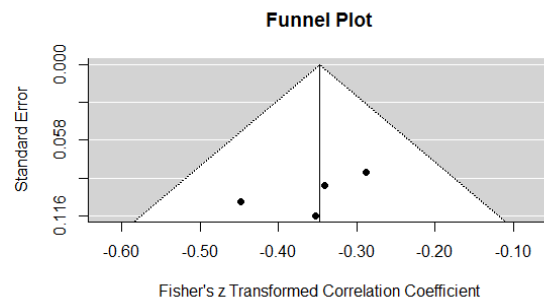


Figure 64. Physical Functioning and Cyclical Timeline

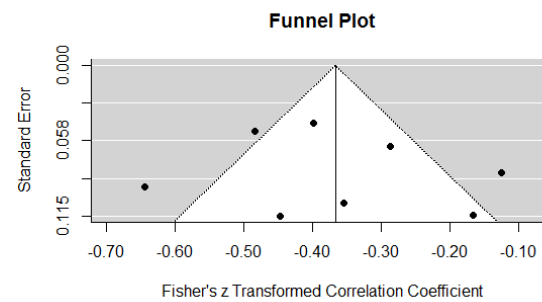


Figure 65. Physical Functioning and Consequences

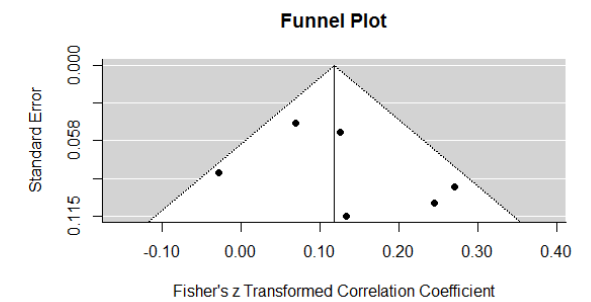


Figure 66. Physical Functioning and Personal Control

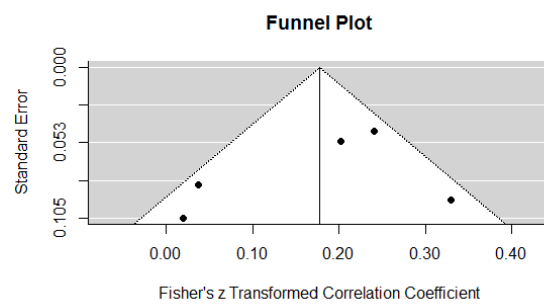


Figure 67. Physical Functioning and Treatment Control

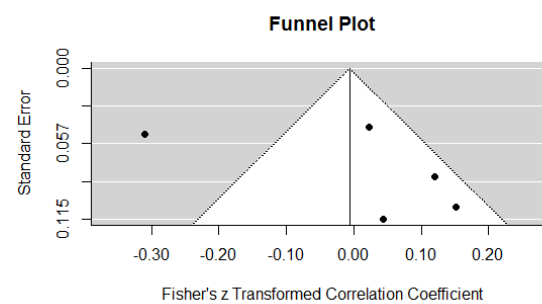


Figure 68. Physical Functioning and Illness Coherence

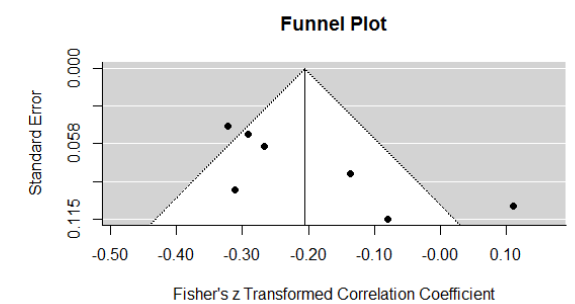


Figure 69. Physical Functioning and Emotional Representations

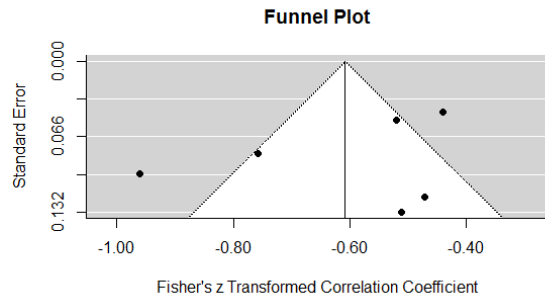


Figure 70. Quality of Life and Identity

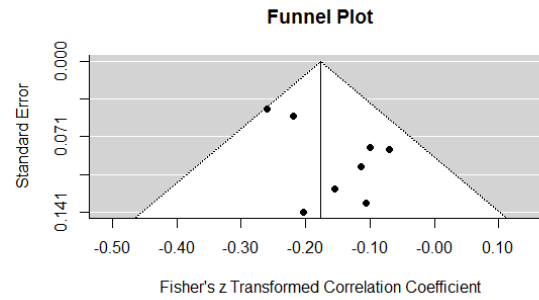


Figure 71. Quality of Life and Acute/Chronic Timeline

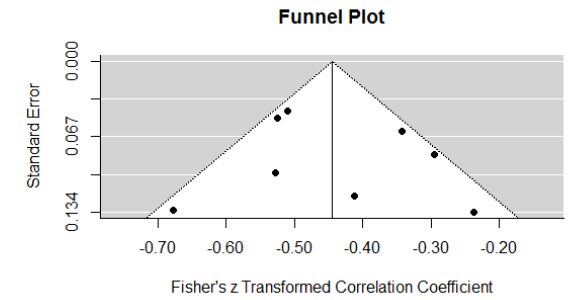


Figure 72. Quality of Life and Consequences

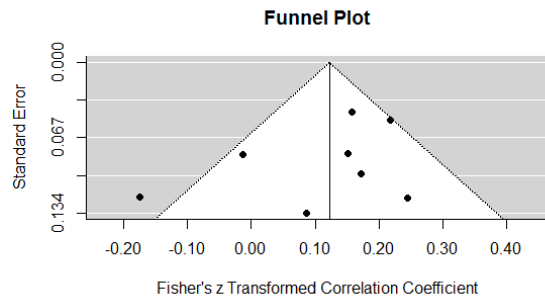


Figure 73. Quality of Life and Personal Control

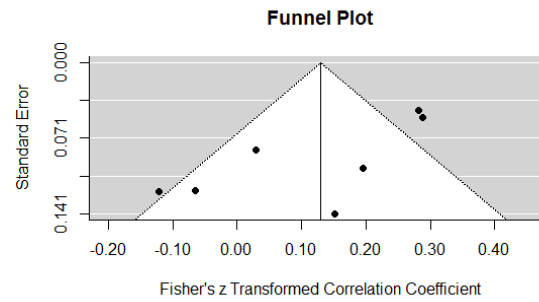


Figure 74. Quality of Life and Treatment Control

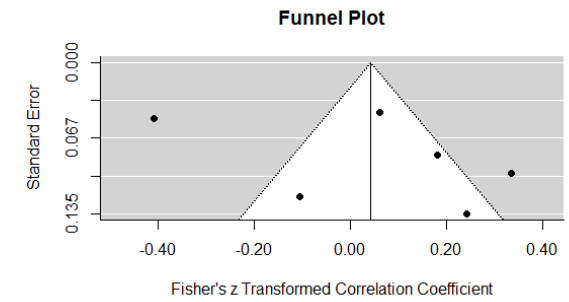


Figure 75. Quality of Life and Illness Coherence

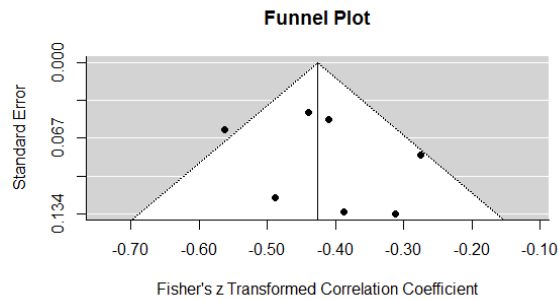


Figure 76. Quality of Life and Emotional Representations

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	51
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	52
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	53-57
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	57
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	N/A
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	58
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	58
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	App 3.2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	58-59, Figure 3.2
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	64
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	59
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	65
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	64
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	64-65

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	67
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	58-59, Figure 3.2
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	65, Table 3.1
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	65-66; App 3.5-3.6
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	66-67, Table 3.2, App 3.7
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	67, App 3.8
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	71-73
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	73-75
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	73, 75
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	N/A

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: [www.prisma-statement.org](http://www.prisma-statement.org).

## Appendix 3.2 Database search strategies (Study 2)

### Scopus Syntax

#### Advanced Search

PUBYEAR > 1995 AND TITLE-ABS-KEY(anxiety OR "anxiety disorder\*" OR depress\* OR "depress\* disorder\*") AND TITLE-ABS-KEY("illness perception\*" OR "illness representation\*" OR "common sense" OR Leventhal\* OR IPQ\*)

### Web of Science Syntax

#### Basic Search

*((anxiety OR "anxiety disorder\*" OR depress\* OR "depress\* disorder\*") AND ("illness perception\*" OR "illness representation\*" OR "common sense" OR Leventhal\* OR IPQ\*))*

Timespan 1995 - 2015

### PubMed Syntax

#### Advanced Search

(anxiety[TIAB] OR "anxiety disorder\*" [TIAB] OR depress\* [TIAB] OR "depress\* disorder\*" [TIAB]) AND ("illness perception\*" [TIAB] OR "illness representation\*" [TIAB] OR "common sense" [TIAB] OR Leventhal\* [TIAB] OR IPQ\* [TIAB])

Custom Date Range 1995 - 2015

### PsycINFO Syntax

#### Command Line

AB, TI(anxiety OR "anxiety disorder\*" OR depress\* OR "depress\* disorder\*") AND AB, TI("illness perception\*" OR "illness representation\*" OR "common sense" OR Leventhal\* OR IPQ\*)

Enter a specific date range starting 1995 ending 2015

### Google Scholar Syntax (1995-2015)

With the exact phrase:

Illness Representation

Illness Perception

Common Sense

Illness Representations

Illness Perceptions

IPQ

With at least one of the words: anxiety depression

In the title of the article

Return articles dated between 1995 - 2015

### Appendix 3.3 Coding manual (Study 2)

## Coding Manual

### 1 General Information

ID No. _____	Depression/Anxiety Type _____	DV _____
--------------	-------------------------------	----------

An article identification number should be included at the top left of each page under **ID No.**, and again in the General Publication Information section of the coding sheet. The 7-digit ID is specified in BLOCK CAPITALS. It is composed of:

- the first three letters of the surname of the first author
- the last two digits of the publication year
- the first two letters of the surname of the second author (if no secondary author: xx)

If several **depression/anxiety types** are examined in a publication, a private coding sheet is filled out for each type of depression/anxiety. The depression/anxiety types in an article are numbered. This number is entered in the upper right corner of each page under **Depression/Anxiety Type**, and again in the Depression/Anxiety and Sample Information section of the coding sheet. If the publication examines only one depression/anxiety type, the number of the depression/anxiety type followed by the word “only” is entered here. **Depression/Anxiety Type** should be coded as per the categories below:

- 1 = Depression  
2 = Anxiety

*Note:* Please include a more specific description of the depression/anxiety type in the Depression/Anxiety and Sample Information section of the coding sheet if necessary.

If in the publication several **dependent variables** (including separate subscales) are analysed (e.g. psychological distress, and avoidance/denial), each dependent variable is given a number in terms of its DV (Subscale) Type. This number is entered in the upper right corner of each page under **DV**, and again in the dependent variable section of the coding sheet. These numbers are the same for all depression/anxiety types. DV (Subscale) Type has been adopted from Hagger and Orbell (2003) and should be coded as per the categories below:

<b>Coping Behaviours</b>	<b>Illness Outcomes</b>
23. Expressing Emotion	33. Affect (Negative/Positive)
24. Cognitive Reappraisal	34. Anxiety
25. Avoidance/Denial	35. Depression
26. Problem-Focused Coping (Generic)	36. Psychological Distress
27. Problem-Focused Coping (Specific - Other)	37. Treatment Related Distress
28. Treatment Decision Making	38. Decisional Uncertainty / Regret
29. Medication Adherence	39. Psychological Well-Being
30. Adherence to Treatment Visits	40. Vitality
31. Doctors Visits	41. Role Functioning
32. Seeking Social Support	42. Physical Functioning
98. Other Coping Behaviour (Specify)	43. Disease State
	44. Quality of Life
	99. Other Illness Outcome (Specify)

### Redundant Information

If multiple coding sheets are filled in for one article, the details that apply to the entire article should be recorded in only one coding sheet, and the corresponding check box (to the right of the questions) should be ticked in other relevant coding sheets.

Therefore a ticked box means that the missing information may be taken from another coding sheet.

### Missing Information

There are two types of missing information:

- Not Applicable: is crossed out in coding sheet and later encoded in data entry with 777.
- Missing: is left open (and possibly supplemented, if one has written to the author).

### Decimal Places

All sample values should be a maximum of two decimal places (rounded).

All statistical values should be a maximum of three decimal places.

### Exclusion Criteria

If one of the following criteria apply, the study must be excluded:

- Study did not use the IPQ or IPQ-R: The study did not measure Illness Representations from the CSM using the Illness Perception Questionnaire or the Revised Illness Perception Questionnaire.
- Study did not measure Coping Behaviours or Illness Outcomes
- Study contained Participants without a Diagnosis of Depression or Anxiety
- Study used (only) Children or Adolescents: Participants must not be under the age of eighteen.
- Study in a language other than English or German: *Note*: We will consider studies in other languages if they include clear results.
- Study was conducted prior to 1995: The study was conducted prior to the creation of the IPQ.

A coding sheet must be created for any excluded study. However, it is sufficient to only fill in the general information for publication section. In addition, the “Study will be Excluded” box should be ticked and reasons should be provided in the comments box on the last page.

## 2 Comments on the Study

<input type="checkbox"/> Study will be Excluded	<input type="checkbox"/> Write to Authors	<input type="checkbox"/> Important Comments
---	---	---

If problems occurred during encoding, the relevant box should be ticked (with details to be included in the Final Details box on the last page of the coding sheet).

- Study will be Excluded: Reason for exclusion in the final data set.
- Write to Authors: If the publication is lacking important statistical information (e.g. information about the sample size or standard deviations), the coder will try to check this information with the authors. The missing details are mentioned in the Final Details box.
- Important Comments: If any problems/comments are entered in the Final Details box, this field should be ticked – unless these are reasons for exclusion or information about a lack of statistical information.



### 3 General Publication Information

Article Identification Number (ID-No.): \_ \_ \_ \_ \_

Study in Article: \_\_\_\_\_

The Article Identification Number should be the same 7-digit ID (specified in BLOCK CAPITALS) as appears at the top left hand corner of each page. It is composed of

- the first three letters of the surname of the first author
- the last two digits of the publication year
- the first two letters of the surname of the second author (if no secondary author: xx)

If the publication contains several studies that refer to different samples, these studies are numbered. For each study, a separate coding sheet should be created. The respective number of the study is then given here.

Coder: \_\_\_\_\_

Coding Date \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Time of Day: \_\_\_\_\_

Coder: Enter initials of Coder

Coding Date: Day / Month / Year

Time of Day: Specify at the start of encoding in order to determine the total duration of coding

Authors: \_\_\_\_\_

Publication Year: \_\_\_\_\_

Specify the last name of the first three authors. If more than three authors are mentioned, all the other authors are abbreviated with **et al.** The publication year is four digits.

Title (first six words): \_\_\_\_\_

Note the first six words from the title of the publication.

Country of Origin - Author: \_\_\_\_\_

Other Origin: \_\_\_\_\_

The Country of Origin of the first author is usually noted on the publication. If not, it should be googled and entered using the codes below. If the author has more than one Country of Origin, enter this under Other Origin.

Coding of Country of Origin

- 1 = USA
- 2 = Canada
- 3 = Germany
- 4 = Great Britain
- 5 = Netherlands
- 6 = Scandinavia
- 7 = Australia
- 8 = Western Europe (excluding G, GB, N, Scandinavia)
- 9 = Eastern Europe (including Russia)
- 99 = Other (Specify)

Discipline of the First Author: \_\_\_\_\_

Other Discipline: \_\_\_\_\_

The discipline of the first author is usually noted on the publication. If not, it should be googled and entered using the codes below. If the author has more than one discipline listed, enter this under Other Discipline.

Coding of Discipline

- 1 = Psychology
- 2 = Psychiatry
- 3 = Medicine
- 4 = Sociology
- 5 = Economy
- 6 = Education
- 99 = Other

Publication Found In: \_\_\_\_\_

Other Place Publication Found: \_\_\_\_\_

Coding where the Publication was Found

- 1 = Scopus
- 2 = Web of Science
- 3 = PubMed
- 4 = PsycINFO
- 5 = Google Scholar
- 6 = Manual Search in Journals
- 7 = Hand-Searches Reference Lists
- 8 = Contact with Researchers
- 99 = Other Source

*Note:* Some publications may be found (or exist) in more than one location or database. The code given will reflect the first place the coders have found the publication.

Type of Publication: _____ Other Publication: _____ Citations: _____ Impact: _____
--

### Coding the Type of Publication

- 1 = Journal with Peer Review
- 2 = Journal without Peer Review
- 3 = Book / Book Chapters
- 4 = Dissertation (PhD)
- 5 = Honours Thesis or Master's Thesis (or German Diploma)
- 6 = Conference Presentation / Poster (Abstract or Full Paper)
- 7 = Unpublished Manuscript
- 8 = Internet Document
- 99 = Other

### Citations

How many citations does the study have (in Scopus)?

### Impact

What is the Impact Factor of the Journal (in Journal Citation Reports)?

## 4 Description of the Study

Study Type: _____	IPQ or IPQ-R Dimension: _____
Reliability Source: _____	Coefficients Type: _____
Number of Items: _____	
Study: _____	

### Coding of Study Type

- 1 = Cross-Sectional
- 2 = Longitudinal
- 3 = Experimental
- 4 = Pseudo-Experimental
- 5 = Qualitative
- 99 = Other Study Type

### Coding of IPQ or IPQ-R Dimension

- 1 = Identity
- 2 = Cause (Generic)
- 3 = Timeline (Acute/Chronic)
- 4 = Consequences
- 5 = Personal Control
- 6 = Treatment Control Items
- 7 = Illness Coherence Items
- 8 = Timeline Cyclical
- 9 = Emotional Representations
- 10 = IPQ Only – Cure-Control
- 11 = All Dimensions of IPQ
- 12 = All Dimensions of IPQ-R

### Coding of Reliability Source

- 0 = No Information
- 1 = No Information, but reference to another publication (specify study)
- 2 = Yes, calculated using the sample from this publication (specify values)
- 3 = Yes, calculated using a different sample (values and specify study)

If reliability coefficients are given for individual subscales, these should be included later in the coding sheet (in the Statistical Analyses and Effect Sizes section).

If coefficients are drawn from both this sample (coding 2) and from other studies (coding 3) in the publication, only the coefficients of the concrete sample are to be coded.

If there is no information about reliability, but there is a reference in the description of the instrument, this corresponds to Coding 1.

### Coding of Coefficient Type

- 1 = Internal Consistency, E.g. Cronbach's  $\alpha$
- 2 = Split- Halves Reliability
- 3 = Test-Retest Reliability
- 4 = Parallel Test Reliability
- 5 = Mean Value of Several Coefficients
- 6 = No Precise Indication
- 99 = Other Coefficient

### Study

If a reliability coefficient is (or is not) stated, and reference is made to another study, the first three authors and the year of publication of the study are stated under "Study".

### Number of Items

If all dimensions of the IPQ or IPQ-R were measured, provide the number of items for the entire measure here. The number of items for each individual subscale should be included later in the coding sheet (in the Statistical Analyses and Effect Sizes section).

If Experimental:		
Number of Groups: _____	Group a: _____	Group c: _____
Assignment: _____	Group b: _____	Group d: _____

The values of various groups are often reported, e.g. for women and for men. In this case, the statistics for each group are reported on a single coding sheet.

*Note:* Only fill out this section of the coding sheet if the study is experimental.

### Number of Groups

Specify the number of groups for which statistics are available. If only one group is available, use a 1. Further, all other fields must not be filled in, but instead crossed out and encoded with 777 (not applicable).

### Assignment

Group allocation:

1 = Randomisation: The subjects were randomly assigned to the groups.

2 = Matched Groups: Each person of one group matches a person of the other group. Each pair has similar properties (e.g. the same age or the same sex).

3 = Natural Groups, parallelised: E.g., women's and men's groups are natural groups. These two groups can also be parallelised for other characteristics (e.g. by having the same mean age).

4 = Natural Groups without further assignment: E.g., comparison of women and men, without other sampling features.

### Group a, Group b, etc.

Each group is assigned a continuous index a, b, c, etc. Note which identify groups, e.g. group a = men, group b = women, or group a = pre-treatment, group b = peri-treatment, group c = post-treatment.

If more than four groups were analysed, the other group affiliations are simply noted on the margin or on a separate piece of paper.

Number of Measurement Points: _____	Year of the First Data Collection: _____
-------------------------------------	--

Number of Measurement Points: Enter a number or **99**, when the number of measurement times varied within the sample. These are only included when statistical information is available for the measurement point.

Year of the First Data Collection: Enter the four-digit year number. If given several years for the first MP, the earliest year is coded.

Lag Between Assessments _____:	MP 5 _____
MP 2 _____	MP 6 _____
MP 3 _____	MP 7 _____
MP 4 _____	MP 8 _____

This box can only be filled in if the distance between the MPs is the same for all individuals, and if statistics are available. The time interval is specified *in months* (rounded if necessary).

Use this scale for the conversion of years, weeks and days into months:

1 Day = 0.03 Months

1 Week = 0.25 Months

1 Year = 12 Months

## 5 Depression/Anxiety and Sample Information

The information on the sample should refer to the smallest unit of analysis (e.g., males and females separately). If there are several groups, information on the sample for each group should be recorded separately. If this is not possible and only information on the total sample can be accessed, it is sufficient to fill in the Depression/Anxiety and Sample Information box on a single coding sheet and to tick the box on the right – meaning that this data is applicable across all groups.

Sometimes statistics are only available at the group level, and other times only for the entire sample. In this case, you can mark information as generally applicable by placing a tick in the smaller box to the right of each row. A ticked box means that this information refers to the whole sample. If this box is not ticked, it means that this information refers to the specific group.

Type of Sample: \_\_\_\_\_

The nature of the sample may change during a longitudinal study. For example, students might participate, and after a passage of time, leave the university. It is therefore crucial for to identify what the type of sample was at the first MP.

### Coding the Type of Sample

- 1 = Representative Sample
- 2 = Non-representative Sample of the general population (specify if the study has a name)
- 3 = Students
- 4 = Clinical Sample (E.g. those assessed in a hospital)
- 5 = Depression/Anxiety Groups, Societies, and Communities (E.g. self-help groups, internet communities)
- 99 = Other type of Sample (specify)

Dep/Anx Type: \_\_\_\_\_

☐

### Coding of Dep/Anx Type

**Depression/Anxiety Type** should be coded as per the categories below:

- 1 = Depression
- 2 = Anxiety

*Note:* Please include a more specific description of the depression/anxiety type in the Depression/Anxiety and Sample Information section of the coding sheet if necessary.

Dep/Anx Duration: M = \_\_\_\_\_ SD = \_\_\_\_\_ Range from \_\_\_\_\_ to \_\_\_\_\_ ☐

Dep/Anx Duration: Record information here regarding the length of time participants have suffered from (been diagnosed with) depression or anxiety (in months).

Use this scale for the conversion of years, weeks and days into months:

1 Day = 0.03 Months

1 Week = 0.25 Months

1 Year = 12 Months

M: Mean value.

SD: Standard deviation.

Range: Specify a minimum and maximum Depression/Anxiety Duration.

Age at Onset: M = \_\_\_\_\_ SD = \_\_\_\_\_ Range from \_\_\_\_\_ to \_\_\_\_\_ ☐

Age at Onset: Record information here regarding which age participants were diagnosed with depression or anxiety (in years).

M: Mean value.

SD: Standard deviation.

Range: Specify a minimum and maximum Age at Onset.

Treatment Type: \_\_\_\_\_ Treatment Stage: \_\_\_\_\_ ☐

#### Coding of Treatment Type

- 1 = Psychological (Specify)
- 2 = Antidepressant Medication
- 3 = Other Medication (Specify)
- 99 = Other Treatment (Specify)

#### Coding of Treatment Stage

- 1 = Pre-Treatment
- 2 = Peri-Treatment (Currently Undergoing Treatment)
- 3 = Post-Treatment

Size of the Sample at each Measurement Point: ☐

MP 1 \_\_\_\_\_

MP 5 \_\_\_\_\_

MP 2 \_\_\_\_\_

MP 6 \_\_\_\_\_

MP 3 \_\_\_\_\_

MP 7 \_\_\_\_\_

MP 4 \_\_\_\_\_

MP 8 \_\_\_\_\_



Here the sample size at each measurement time point is indicated. Sample size includes all participants, regardless of whether or not they were later excluded from the analysis. The point is to show how the sample has changed over time (i.e. mostly reduced).

If multiple groups are examined separately, only the respective group size is specified.

Total N: _____	Retention Rate: _____ %	<input type="checkbox"/>
----------------	-------------------------	--------------------------

Total N: The number of individuals that participated at all time points.

Retention Rate: How high is the percentage of those who have participated in all MPs (total N), compared to the sample for the first MP (can be calculated from the ratio of MP 1 and total N).

Proportion of Men at MP 1: _____ %	<input type="checkbox"/>
------------------------------------	--------------------------

Proportion of Men: Always indicate the MP for which the proportion of men refers.

Age at MP 1 ____: M = _____ SD = _____ Range from _____ to _____	<input type="checkbox"/>
--	--------------------------

Age at MP 1: Specify to whom the information relates. If data is available for several MPs, the information for MP 1 is reported.

M: Mean value.

SD: Standard deviation.

Range: Specify a minimum and maximum age.

Ethnicity: ____ Other Ethnicity: ____ Country of Origin: ____ Other Country of Origin: ____	<input type="checkbox"/>
---	--------------------------

#### Coding of Ethnicity

Ethnicity is specified only if the proportion of this ethnic group makes up a minimum of 50% of the sample.

1 = White (Caucasian, Anglo-American, European)

2 = Black

3 = Hispanic

4 = Indigenous People

5 = Asian

6 = Mixed (when two ethnic groups are represented with 50% each)

99 = Other (specify)

Coding of Country of Origin

Specify in which Country the study was conducted.

- 1 = USA
- 2 = Canada
- 3 = Germany
- 4 = Great Britain
- 5 = Netherlands
- 6 = Scandinavia
- 7 = Australia
- 8 = Western Europe (excluding G, GB, N, Scandinavia)
- 9 = Eastern Europe (including Russia)
- 99 = Other (Specify)

## 6 Dependent Variable

No. \_\_\_\_\_ Did the Study aim to change the Dependent Variable? \_\_\_\_\_

### Number of Dependent Variables

If there are several DVs (including separate subscales), the DVs are numbered in terms of their DV (Subscale) Type and a separate coding sheet for each DV is created. This number should also be entered in the top right hand corner of every page. *Note.* As each subscale can be a DV of its own, the number of DVs should include subscales (if their details are to be recorded separately throughout the coding sheet). At “No.” the number of DVs is given.

If only one DV is encoded, this field is crossed out and later coded with 777 (not applicable).

### Did the Study aim to change the Dependent Variable/s?

Did the study aim to change the DV:

0 = No

1 = Yes

DV Global: \_\_\_\_\_ DV Name: \_\_\_\_\_

There are three aspects of the DV that need to be coded. In DV Global, the global category is entered. These are distinguished as:

1 = Coping Behaviour

2 = Illness Outcome

99 = Other (Please Specify)

DV Name indicates the name of the DV which is used in the publication.

Subscale: \_\_\_\_\_ DV (Subscale) Type: \_\_\_\_\_

### Subscale

If only one subscale of an instrument is used, or if data is provided separately for several subscales, this is noted here (by recording the name of the subscale). All other information (e.g., reliability and number of items) will always refer to this subscale, and not the entire instrument.

DV (Subscale) Type has been adopted from Hagger and Orbell (2003) and should be coded as per the categories below:

Coping Behaviours	Illness Outcomes
-------------------	------------------

23. Expressing Emotion	33. Affect (Negative/Positive)
24. Cognitive Reappraisal	34. Anxiety
25. Avoidance/Denial	35. Depression
26. Problem-Focused Coping (Generic)	36. Psychological Distress
27. Problem-Focused Coping (Specific - Other)	37. Treatment Related Distress
28. Treatment Decision Making	38. Decisional Uncertainty / Regret
29. Medication Adherence	39. Psychological Well-Being
30. Adherence to Treatment Visits	40. Vitality
31. Doctors Visits	41. Role Functioning
32. Seeking Social Support	42. Physical Functioning
98. Other Coping Behaviour (Specify)	43. Disease State
	44. Quality of Life
	99. Other Illness Outcome (Specify)

Data Source: \_\_\_\_\_ Additional Information: \_\_\_\_\_

### Coding of the Data Source

- 1 = Self-report Questionnaire
- 2 = Self-report Interview
- 3 = Self-report on Ambulatory Assessment
- 5 = Observation
- 6 = Ratings by Others (include who provided the ratings)
- 7 = Analysis of Written Reports (e.g., diaries or autobiographies)
- 8 = Physiological Measures
- 9 = Objective Measures (e.g., pill bottle count)
- 99 = Other Data Source

*Caution:* The use of a scale does not always mean that the data source is a self-report questionnaire. Often the scales are presented in an interview, making it a self-report interview.

Instrument:    Code: _____    Number of Items: _____							
Reliability:	Coefficients:	MP ____	MP ____	MP ____	MP ____	MP ____	MP ____
Source: _____	Type: _____	_____	_____	_____	_____	_____	_____
Study: _____							

### Coding of the Instrument

#### **Measures of Coping Behaviours**

- 1 = COPE (Carver, Scheier, & Weintraub, 1989)
- 2 = Utrecht Coping Questionnaire (UCL; Schreurs, & Willige, 1988)
- 3 = Impact of Event Scale - Revised (IES-R; Weiss & Marmar, 1997)
- 4 = Ways of Coping Checklist - Revised (WCCL-R; Vitaliano, Russo, Carr, Maiuro, & Becker)
- 5 = Ways of Coping Questionnaire (WCQ; Folkman & Lazarus, 1988)
- 6 = Medication Adherence Reporting Scale - 5 (MARS-5; Horne, 2001)
- 7 = The Morisky Medication Adherence Scale - 8 (MMAS-8; Morisky, Green, & Levine, 1986)
- 8 = Other Measure of Coping Behaviour (Specify)

#### **Measures of Illness Outcomes**

- 9 = Medical Outcomes Study 36/20/12 Item Short Form (MOS SF-36/20/12; Stewart, Hays, & Ware, 1988)
- 10 = General Health Questionnaire 60/30/28/12 Item (GHQ-60/30/28/12; Goldberg, 1978)
- 11 = Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988)
- 12 = Generalised Anxiety Disorder 7-Item Scale (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006)
- 13 = State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983)

- 14 = Centre for Epidemiological Studies Depression Scale Revised (CESD-R; Eaton, Muntaner, Smith, Tien, & Ybarra, 2004)
- 15 = Patient Health Questionnaire – 2/9 Item (PHQ-9/2; Kroenke, & Spitzer, 2002; Kroenke, Spitzer, & Williams, 2003)
- 16 = Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)
- 17 = Impact of Event Scale – Revised (IES-R; Weiss & Marmar 1996)
- 18 = Psychological Adjustment to Illness Scale – Self Report (PAIS-SR; Derogatis, 1986)
- 19 = Penn State Worry Questionnaire (PSWQ; Meyer, Miller, Metzger, & Borkovec, 1990)
- 20 = Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)
- 21 = Well-being Questionnaire (WB-Q12 or WB-Q22; Bradley, 1994)
- 22 = World Health Organisation Quality of Life (or BREF) (WHOQOL; WHO, 1998)
- 23 = Other Measure of Illness Outcome (Specify)

### Number of Items

Number of items specifies the number of items the construct was measured with. If only one subscale is used, only list the number of items for this subscale.

### Source of Reliability Information

- 0 = No Information
- 1 = No Information, but reference to another publication (specify study)
- 2 = Yes, calculated using the sample from this publication (specify values)
- 3 = Yes, calculated using a different sample (values and specify study)

If there is no information about reliability, but there is a reference in the description of the instrument, this corresponds to Coding 1.

If coefficients are drawn from both this sample (coding 2) and from other studies (coding 3) in the publication, only the coefficients of the concrete sample are to be coded.

### Type of Reliability Coefficient

- 1 = Internal Consistency, E.g. Cronbach's  $\alpha$
- 2 = Split- Halves Reliability
- 3 = Test-Retest Reliability
- 4 = Parallel Test Reliability
- 5 = Mean Value of Several Coefficients
- 6 = No Precise Indication
- 99 = Other Coefficient

### MPs for Reliability Coefficients

If a reliability coefficient is given, it is placed in the small table. These should be noted at each MP, for as far as possible. If several reliability coefficients exist for a MP (eg, Cronbach's alpha and split-half coefficient), only report Cronbach's alpha.

If only one reliability coefficient is given for the study, cross out other MP boxes.

If a reliability coefficient is not given, but reference is made to another study, the coefficient from that study should be provided in (beneath) the first MP box, with no number given to the MP itself.

### Study

If a reliability coefficient is (or is not) stated, and reference is made to another study, the first three authors and the year of publication of the study are stated under "Study".



If correlation coefficients are provided, please include the type of correlation in the top left hand corner of the correlation and reliabilities table.

If cause is included in the data set, provide relevant details in the Final Details box.

If bivariate correlations between different time points are reported, these can be specified here.  $N$  is the size of the sample. At  $t_1$  and  $t_2$  place the relevant MP details. The correlation is given at  $r$ . The  $p$ -value is given at  $p$ .

If correlation coefficients are provided, regression weights **do not** need to be recorded.

If no correlation data is provided, this should be noted in the Final Details box and the Write to Authors box on the front page of the coding sheet should be ticked.

IPQ reliability coefficients for one or two MPs can be entered in this table. If there is only one MP, cross out the other MP box.

For each subscale reported, provide the relevant coefficient at *Coeff.*, and the number of items included in that subscale at *Items*.

#### Regressions

	Time 1								Time 2							
	Standardised Regression Coefficients				Unstandardised Regression Coefficients				Standardised Regression Coefficients				Unstandardised Regression Coefficients			
	$\beta$	$SE$	$df$	$p$	$B$	$SE$	$df$	$p$	$\beta$	$SE$	$df$	$p$	$B$	$SE$	$df$	$p$
Identity																
Cause (generic)																
Timeline (acute/chronic)																
Timeline Cyclical																
Consequence																
Personal Control																
Treatment Control																
Illness Coherence																
Emotional Representations																

The standardised ( $\beta$ ) and unstandardised ( $B$ ) regression coefficients should be reported here. In addition, the standard error ( $SE$ ), the degrees of freedom ( $df$ ) and  $p$ -value ( $p$ ) of the coefficient should be coded.

Source of Statistical Information

Page: \_\_\_\_\_

Table/Graph: \_\_\_\_\_

In order to find the statistical information quickly, record the page number, and if applicable, the number of the table or graph from which the information was collected. If the statistical information was taken from the text, enter “text” here.

Moderator Variables: \_\_\_\_\_

Other Moderator Variables (Authors' Term): \_\_\_\_\_

If Moderator Variables of the relationship between Illness Perceptions and Outcomes have been examined, provide information here.

#### Coding of Moderator Variables

- 1 = Social Support
- 3 = Extraversion
- 4 = Neuroticism
- 5 = Other Personality Characteristics (E.g. Optimism, Self-Esteem, etc.)
- 6 = Previous Experience with Depression/Anxiety
- 7 = Socio-Economic Status
- 8 = Age
- 9 = Number of Other Illnesses
- 10 = Coping Strategies
- 99 = Other (Specify)



## 8 Concluding Information

Time for Coding: \_\_\_\_\_ minutes

Problems/Comments:

Study Interpretation:

At the end of coding an article, the time needed for encoding should be noted.

In addition, there is space for problems and comments. If information is missing, the missing information should be listed here.

Finally, include a brief interpretation of the study in this box. This can be transcribed or taken directly from the publication abstract.

**Appendix 3.4** Coding sheet (Study 2)

ID No. \_\_\_\_\_

Depression/Anxiety Type \_\_\_\_\_ DV \_\_\_\_\_

Comments on the study



Study will be Excluded



Write to Authors



Important Comments

General Publication Information

Article Identification Number (ID-No.): \_\_\_\_\_ Study in Article: \_\_\_\_\_

Coder: \_\_\_\_\_ Coding Date \_\_\_\_ / \_\_\_\_ / \_\_\_\_ Time of Day: \_\_\_\_\_

Authors: \_\_\_\_\_ Publication Year: \_\_\_\_\_

Title (first six words): \_\_\_\_\_

Country of Origin - Author: \_\_\_\_\_ Other Origin: \_\_\_\_\_

Discipline of the First Author: \_\_\_\_\_ Other Discipline: \_\_\_\_\_

Publication Found In: \_\_\_\_\_ Other Place Publication Found: \_\_\_\_\_

Type of Publication: \_\_\_\_\_ Other Publication: \_\_\_\_\_ Citations: \_\_\_\_\_ Impact: \_\_\_\_\_

Description of the Study

Study Type: \_\_\_\_\_ IPQ or IPQ-R Dimension: \_\_\_\_\_

Reliability Source: \_\_\_\_\_ Coefficient Type: \_\_\_\_\_ Number of Items: \_\_\_\_\_

Study: \_\_\_\_\_

If Experimental:

Number of Groups: \_\_\_\_\_ Group a: \_\_\_\_\_ Group c: \_\_\_\_\_

Assignment: \_\_\_\_\_ Group b: \_\_\_\_\_ Group d: \_\_\_\_\_

Number of Measurement Points: \_\_\_\_\_ Year of the First Data Collection: \_\_\_\_\_

Lag Between Assessments \_\_\_\_\_: MP 6 \_\_\_\_\_

MP 2 \_\_\_\_\_ MP 7 \_\_\_\_\_

MP 3 \_\_\_\_\_ MP 8 \_\_\_\_\_

MP 4 \_\_\_\_\_ MP 9 \_\_\_\_\_

## Depression/Anxiety and Sample Information

Type of Sample: _____		<input type="checkbox"/>
Dep/Anx Type: _____		<input type="checkbox"/>
Dep/Anx Duration: M = _____	SD = _____ Range from _____ to _____	<input type="checkbox"/>
Age at Onset: M = _____	SD = _____ Range from _____ to _____	<input type="checkbox"/>
Treatment Type: _____	Treatment Stage: _____	<input type="checkbox"/>
		<input type="checkbox"/>
Sample Size at each Measurement Point:		
MP 1 _____	MP 5 _____	
MP 2 _____	MP 6 _____	
MP 3 _____	MP 7 _____	
MP 4 _____	MP 9 _____	
Total-N: _____	Retention Rate: _____ %	<input type="checkbox"/>
Proportion of Men at MP 1: _____ %		<input type="checkbox"/>
Age at MP 1: M = _____ SD = _____ Range from _____ to _____		<input type="checkbox"/>
Ethnicity: ____ Other Ethnicity: ____ Country of Origin: ____ Other Country of Origin: ____		<input type="checkbox"/>

## Dependent Variables

No. _____ Did the Study aim to change the Dependent Variable/s? _____							
DV Global: _____ DV Name: _____							
Subscale: _____				DV (Subscale) Type: _____			
Data Source: _____				Additional Info: _____			
Instrument: Code: _____ Number of Items: _____							
Reliability:	Coefficients:	MP ____	MP ____	MP ____	MP ____	MP ____	MP ____
Source: _____	Type: _____	_____	_____	_____	_____	_____	_____
Study: _____							

Type of Statistics Provided: \_\_\_\_\_

Means, Standard Deviations, and Standard Errors

T1 N = _____			T2 N = _____			T3 N = _____			T4 N = _____		
M	SD	SE	M	SD	SE	M	SD	SE	M	SD	SE
T5 N = _____			T6 N = _____			T7 N = _____			T8 N = _____		
M	SD	SE	M	SD	SE	M	SD	SE	M	SD	SE

☐[illegible]

7

[illegible]

Source of Statistical Information

Page: \_\_\_\_\_

Table/Graph: \_\_\_\_\_



Moderator Variables

Moderator Variables: \_\_\_\_\_

Other Moderator Variables (Authors' Term): \_\_\_\_\_



Final Details

Time for Coding: \_\_\_\_\_ Minutes

Problems/Comments:



Study Interpretation:



**Appendix 3.5** Risk of bias assessment table (Study 2)

<b>Authors (Date)</b>	<b>Study Design</b>	<b>IPQ, IPQ-R, or B-IPQ: Used as recommended</b>	<b>Dimensions assessed (number of items)*</b>	<b>Correlation Analysis</b>	<b>Adjustment for possible confounds</b>	<b>Meta-Analysis or Narrative Review</b>
Akcakaya (2012)	Longitudinal	IPQ-R: Yes - ‘depression’ substituted for ‘illness’	Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson’s Correlation	None	Meta-Analysis
Baines, Wittkowski, & Wieck (2013)	Longitudinal	IPQ-R: Partially - identity and cause scales adapted to suit depression - one emotional representations item removed - two additional answer options included	Identity (14), Cause (21)^, Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (5)	Spearman’s Correlation	None	Meta-Analysis
Brown, Battista, Sereika, Bruehlman, Dunbar-Jacob, & Thase (2007)	Cross-sectional	IPQ: Partially - modified to suit depression - cause items were adapted following factor analysis	Identity (23), Cause (5), Timeline (3), Consequences (7), Controllability (7)	N/A	N/A	Narrative Review
Brown, Dunbar-Jacob, Palenchar, Kelleher, Bruehlman, Sereika, & Thase (2001)	Cross-sectional	IPQ: Partially - modified to suit depression - additional identity and cause items included	<b>Identity (23), Cause (16), Timeline (4), Consequences (7), Controllability (7)</b>	Partial Correlation	Depression Severity	Meta-Analysis
Cabassa, Lagomasino, Dwight-Johnson, Hansen, & Xie (2008)	Cross-sectional	IPQ-R: Partially - modified to suit depression - ‘depression’ substituted for ‘illness’	Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (4), Treatment Control (4)	Unspecified Correlation	None	Meta-Analysis
Elwy, Glickman, Bokhour, Dell, Mueller, Zhao, Osei-Bonsu, Rodrigues, Coldwell, Ngo, Schlosser, Vielhauer, Pirraglia, & Eisen (2013)	Longitudinal	IPQ-R: No - Factor analysis was undertaken for all items to create new subscales	Identity (23 - 5 subscales), Cause (26 - 7 subscales), Timeline - Acute (3) Timeline - Chronic (3), Timeline - Cyclical (3), Consequences (5), Personal Control (7), Treatment Control (3), External Control (4) Illness Coherence (5), Emotional Representations (5)	N/A	N/A	Narrative Review

Elwy, Yeh, Worcester, & Eisen (2011)	Qualitative	CSM Generally: - Qualitative Interview	CSM Generally	N/A	N/A	Narrative Review
Fortune, Barrowclough, & Lobban (2004)	Cross-sectional	IPQ: Yes - 'depression' substituted for 'illness' - identity items were adapted to suit depression	Identity (14), Cause (11)^, Timeline (4), Consequences (7), Control/Cure (6)	Pearson's Correlation	None	Meta-Analysis
Glattacker, Heyduck, & Meffert (2013)	Longitudinal	IPQ-R: Yes - 'depression' substituted for 'illness' - identity items were adapted to suit depression - German version	Identity (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Horn, Kneisler, Schuster, & Traue (2010)	Longitudinal	IPQ-R: Yes - German version	Cause^, Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Unspecified Correlation	None	Meta-Analysis
Houle, Villaggi, Beaulieu, Lespérance, Rondeau, & Lambert (2013)	Cross-sectional	IPQ-R: Yes - 'depression' substituted for 'illness' - cause items were adapted following factor analysis	Cause (18)^, Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Hunot, Horne, Leese, & Churchill (2007)	Longitudinal	IPQ-R: Yes	IPQ-R: Identity (14), Cause (18), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	N/A	N/A	Narrative Review
Kelly, Sereika, Battista, & Brown (2007)	Cross-sectional	IPQ: Yes - cause items were adapted following factor analysis	Identity (14), Cause (23), Timeline (6), Consequences (7), Control/Cure (7), Emotional Reactions (9)	N/A	N/A	Narrative Review

Lu, Tang, Shan Liow, Wei Ni Ng, Su Hui Ho, & Chun Mun Ho (2014)	Cross-sectional	IPQ-R: Partially - modified to suit depression	Identity (14), Timeline - Acute/Chronic (6), Timeline - Cyclical (4), Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Pearson's Correlation	None	Meta-Analysis
Mc Sharry, Bishop, Moss-Morris, & Kendrick (2013)	Qualitative	CSM Generally: - Qualitative Interview	CSM Generally	N/A	N/A	Narrative Review
O'Mahen, Flynn, Chermack, & Marcus (2009)	Longitudinal	IPQ: No - Perinatal depression specific items were added to several subscales	Cause (10), Timeline (3), Consequences (8), Control/Cure (8)	N/A	N/A	Narrative Review
Patel, Wittkowski, Fox, & Wieck (2013)	Qualitative	CSM Generally: - Qualitative Interview	CSM Generally	N/A	N/A	Narrative Review
Vollmann, Scharloo, Salewski, Dienst, Schonauer, & Renner (2010)	Cross-sectional	IPQ-R: Partially - modified to suit depression - identity and cause scales adapted to suit depression	Identity (24)^, Cause (19), Timeline - Acute/Chronic (6), Timeline - Cyclical (4)^, Consequences (6), Personal Control (6), Treatment Control (5), Illness Coherence (5), Emotional Representations (6)	Profile Correlation	None	Meta-Analysis
Ward, Mengesha, & Issa (2014)	Qualitative	CSM Generally: - Qualitative Interview	CSM Generally	N/A	N/A	Narrative Review

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*Note:* \*Dimensions that appear are in bold were assessed by authors but not reported by authors for some outcomes; ^ = items were measured but not assessed



**Appendix 3.6** Risk of bias assessment and figure (Study 2)

Study	Risk of Bias from IPQ Use (Yes vs. Partially vs. No)	Risk of Bias from Design (Cross-sectional vs. Longitudinal)	Adjustment for Confounds (Yes vs. No)	Assessing and Reporting of IPQ Dimensions (Assessed and Reported vs. Assessed and Not Reported vs. Measured and Not Assessed)
- Akcakaya (2012)	1	1	2	1
- Baines, Wittkowski, & Wieck (2013)	2	1	2	3
- Brown, Battista, Sereika, Bruehlman, Dunbar-Jacob, & Thase (2007)	2	2	2	1
- Brown, Dunbar-Jacob, Palenchar, Kelleher, Bruehlman, Sereika, & Thase (2001)	2	2	1	2
- Cabassa, Lagomasino, Dwight- Johnson, Hansen, & Xie (2008)	2	2	2	1
- Elwy, Glickman, Bokhour, Dell, Mueller, Zhao, Osei- Bonsu, Rodrigues, Coldwell, Ngo, Schlosser, Vielhauer, Pirraglia, & Eisen (2013)	3	1	2	1

- Elwy, Yeh, Worcester, & Eisen (2011)	3	3	2	1
- Fortune, Barrowclough, & Lobban (2004)	1	2	2	3
- Glattacker, Heyduck, & Meffert (2013)	1	1	2	1
- Horn, Kneisler, Schuster, & Traue (2010)	1	1	2	3
- Houle, Villaggi, Beaulieu, Lespérance, Rondeau, & Lambert (2013)	1	2	2	3
- Hunot, Horne, Leese, & Churchill (2007)	1	1	2	1
- Kelly, Sereika, Battista, & Brown (2007)	1	2	2	1
- Lu, Tang, Shan Liow, Wei Ni Ng, Su Hui Ho, & Chun Mun Ho (2014)	2	2	2	1
- Mc Sharry, Bishop, Moss- Morris, & Kendrick (2013)	3	3	2	1

- O'Mahen, Flynn, Chermack, & Marcus (2009)	3	1	2	1
- Patel, Wittkowski, Fox, & Wieck (2013)	3	3	2	1
- Vollmann, Scharloo, Salewski, Dienst, Schonauer, & Renner (2010)	2	2	2	3
- Ward, Mengesha, & Issa (2014)	3	3	2	1

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**Key:**

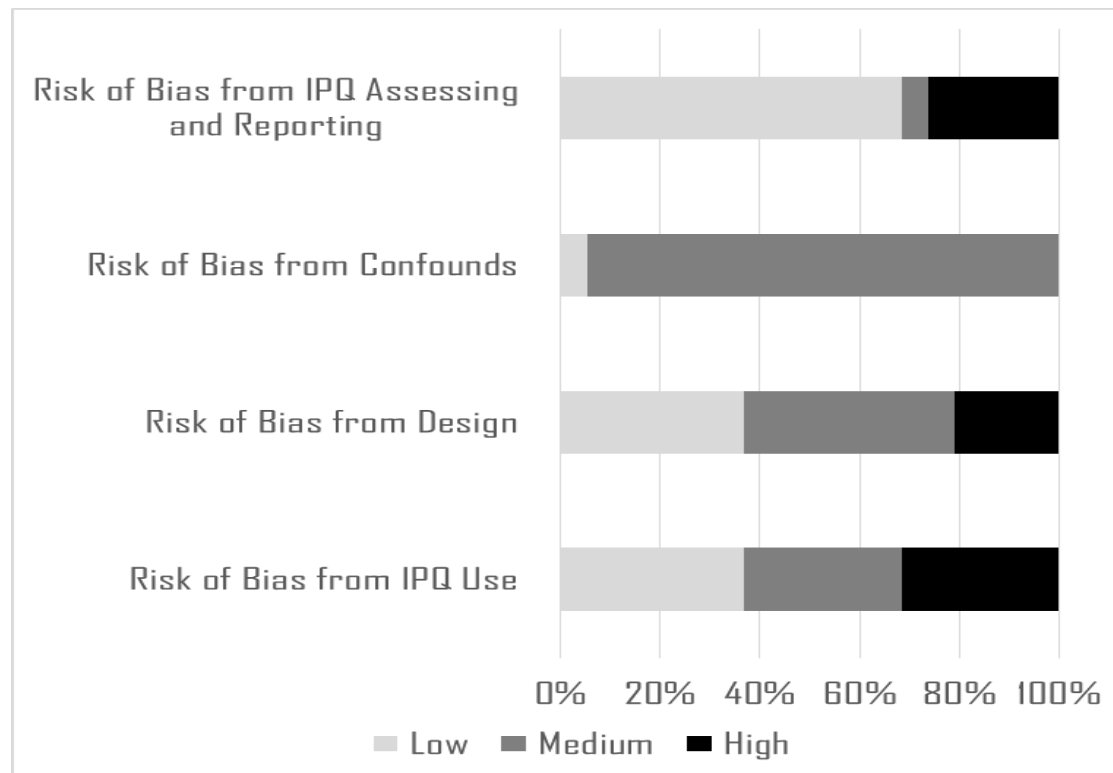

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1 = Yes used IPQ as recommended	1 = Longitudinal	1 = Adjusted for Confounds	1 = Assessed and Reported all measured IPQ Dimensions
2 = Partially used IPQ as recommended	2 = Cross-Sectional	2 = Did not adjust for Confounds	2 = Assessed but did not Report all measured IPQ Dimensions
3 = Did not use IPQ as recommended (or qual study)	3 = Qualitative		3 = Did not Assess nor Report all measured IPQ Dimensions

---

**Scores:**

	Risk of Bias from IPQ Use	Risk of Bias from Design	Risk of Bias from Confounds	Risk of Bias from IPQ Assessing and Reporting
Low	36.84210526	36.84211	5.263158	68.4211
Medium	31.57894737	42.10526	94.73684	5.26316
High	31.57894737	21.05263	0	26.3158



### Appendix 3.7 Meta-analysis forest plots between illness representations and coping and illness representations and psychological distress (Study 2)

Note: See page 302 for the key to each study code.

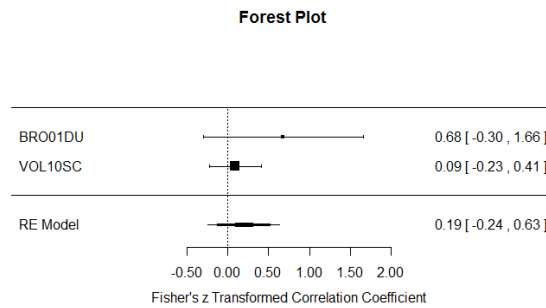


Figure 1. Coping and Cause

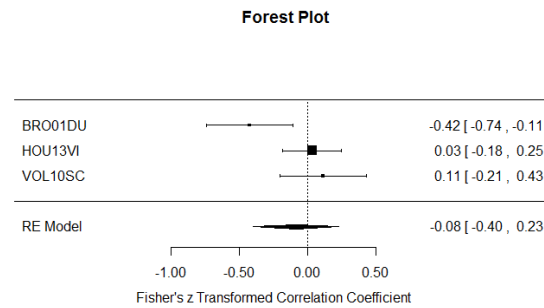


Figure 2. Coping and Acute/Chronic Timeline

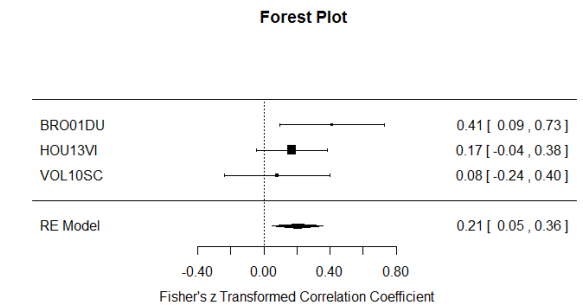


Figure 3. Coping and Consequences

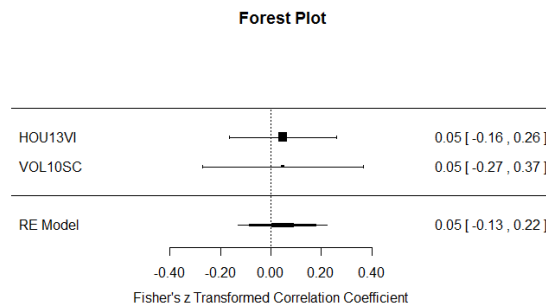


Figure 4. Coping and Personal Control

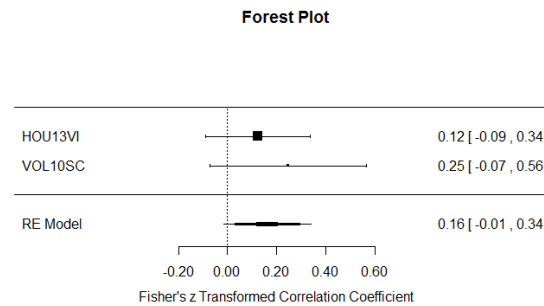


Figure 5. Coping and Treatment Control

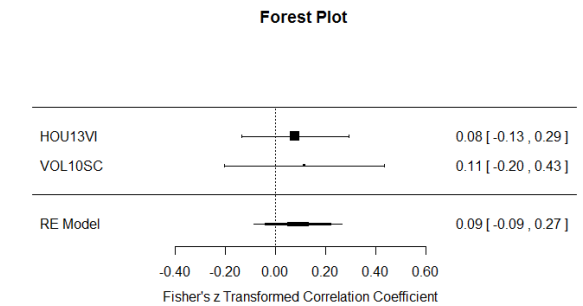


Figure 6. Coping and Illness Coherence

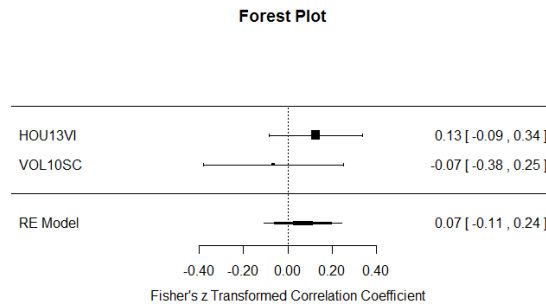


Figure 7. Coping and Emotional Representations

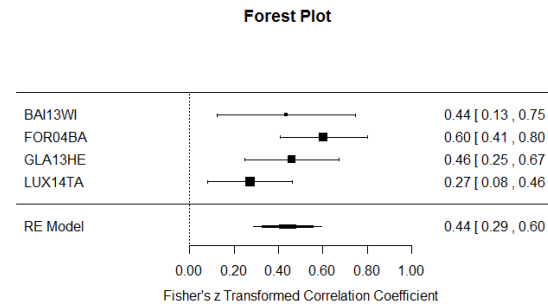


Figure 8. Psychological Distress and Identity

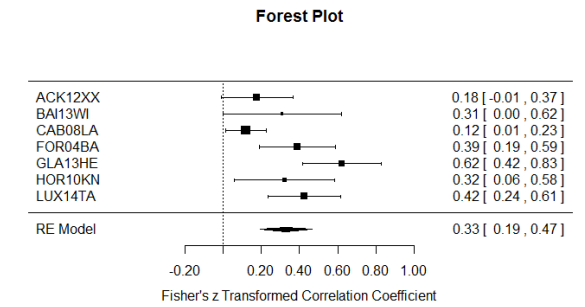


Figure 9. Psychological Distress and Acute/Chronic Timeline

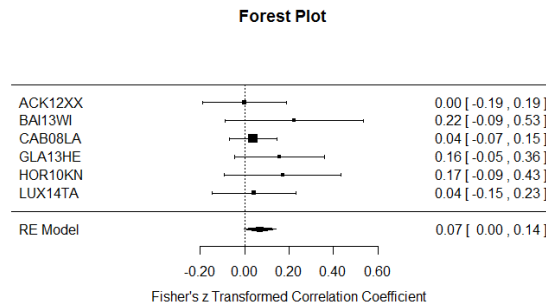


Figure 10. Psychological Distress and Cyclical Timeline

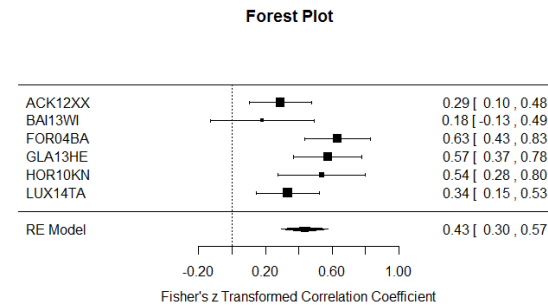


Figure 11. Psychological Distress and Consequences

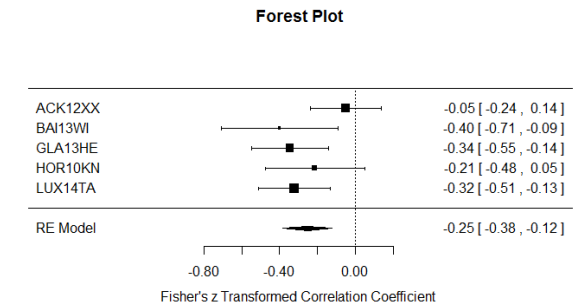


Figure 12. Psychological Distress and Personal Control

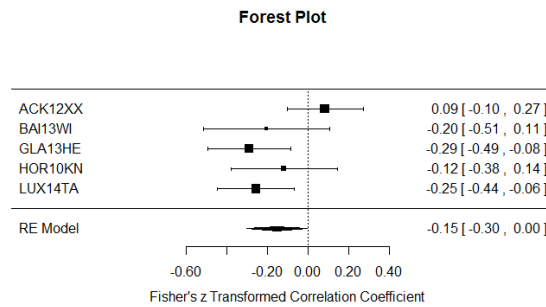


Figure 13. Psychological Distress and Treatment Control

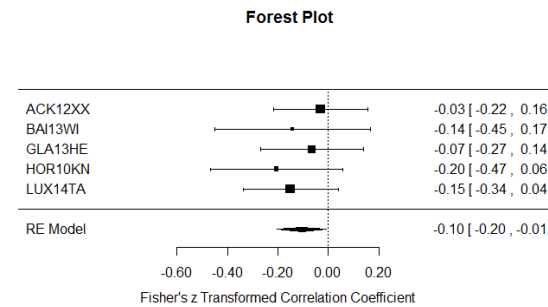


Figure 14. Psychological Distress and Illness Coherence

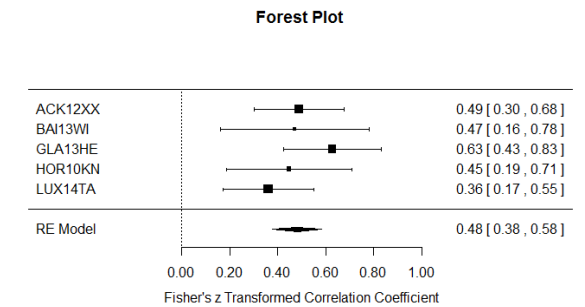


Figure 15. Psychological Distress and Emotional Representations

**Study codes with associated authors and dates**

Study Code	Authors (Date)
ACK12XX	Akcakaya (2012)
BAI13WI	Baines, Wittkowski, & Wieck (2013)
BRO01DU	Brown, Dunbar-Jacob, Palenchar, Kelleher, Bruehlman, Sereika, & Thase (2001)
CAB08LA	Cabassa, Lagomasino, Dwight-Johnson, Hansen, & Xie (2008)
FOR04BA	Fortune, Barrowclough, & Lobban (2004)
GLA13HE	Glattacker, Heyduck, & Meffert (2013)
HOR10KN	Horn, Kneisler, Schuster, & Traue (2010)
HOU13VI	Houle, Villaggi, Beaulieu, Lespérance, Rondeau, & Lambert (2013)
LUX14TA	Lu, Tang, Shan Liow, Wei Ni Ng, Su Hui Ho, & Chun Mun Ho (2014)
VOL10SC	Vollmann, Scharloo, Salewski, Dienst, Schonauer, & Renner (2010)

**Appendix 3.8** Meta-analysis funnel plots between illness representations and coping and illness representations and psychological distress (Study 2)

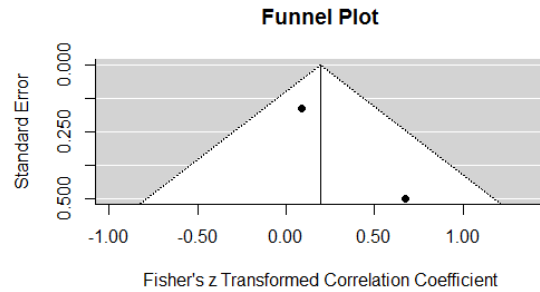


Figure 1. Coping and Cause

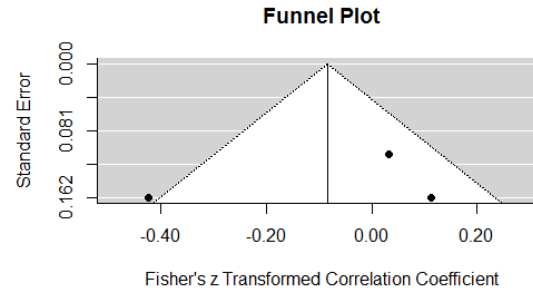


Figure 2. Coping and Acute/Chronic Timeline

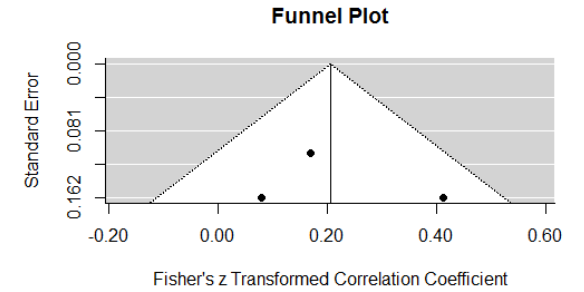


Figure 3. Coping and Consequences

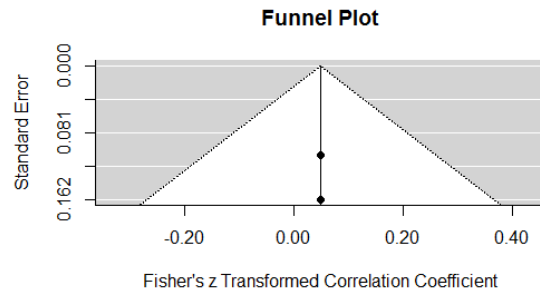


Figure 4. Coping and Personal Control

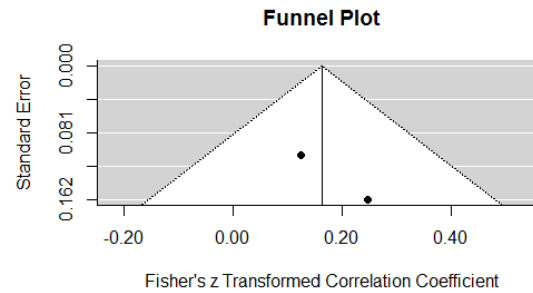


Figure 5. Coping and Treatment Control

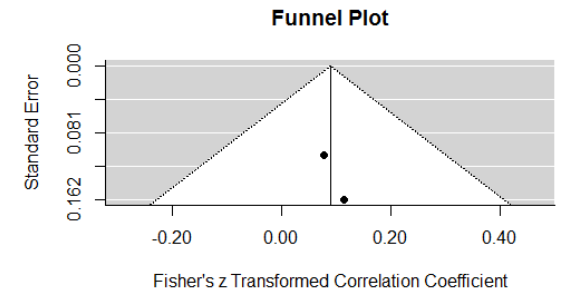


Figure 6. Coping and Illness Coherence



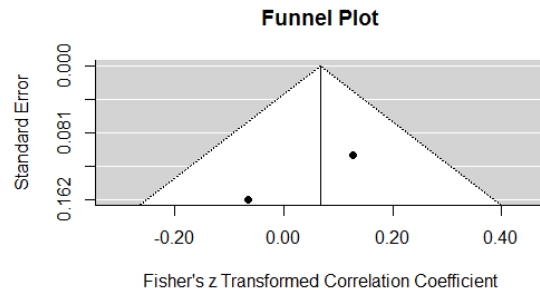


Figure 7. Coping and Emotional Representations

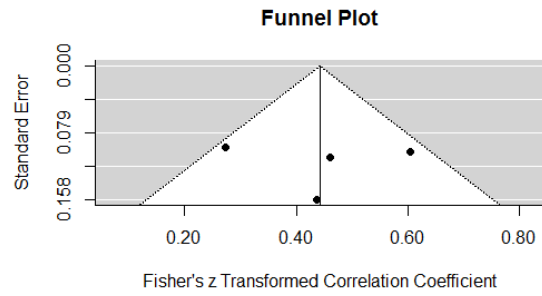


Figure 8. Psychological Distress and Identity

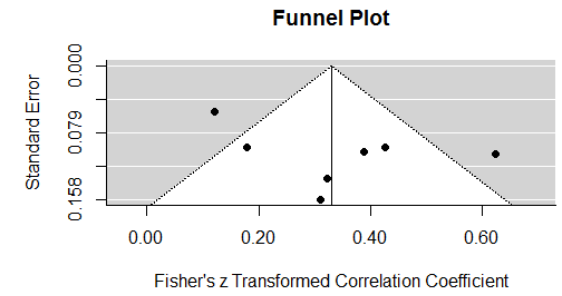


Figure 9. Psychological Distress and Acute/Chronic Timeline

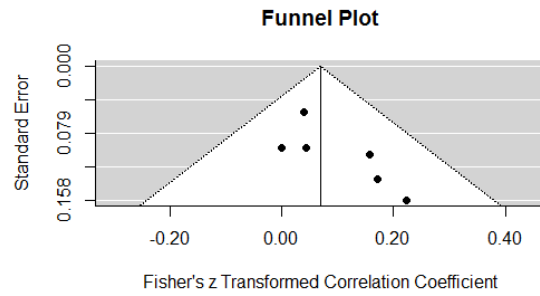


Figure 10. Psychological Distress and Cyclical Timeline

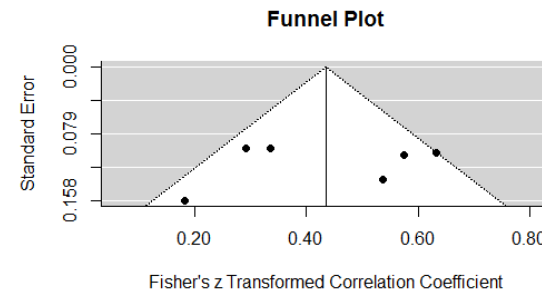


Figure 11. Psychological Distress and Consequences

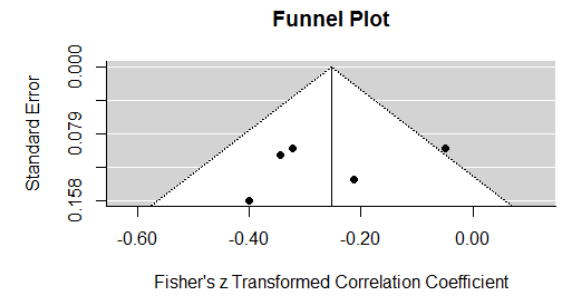


Figure 12. Psychological Distress and Personal Control

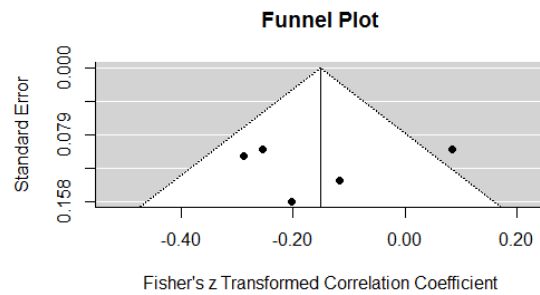


Figure 13. Psychological Distress and Treatment Control

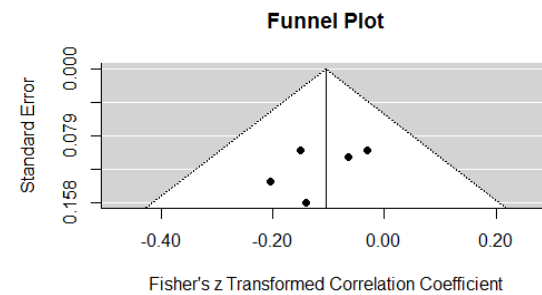


Figure 14. Psychological Distress and Illness Coherence

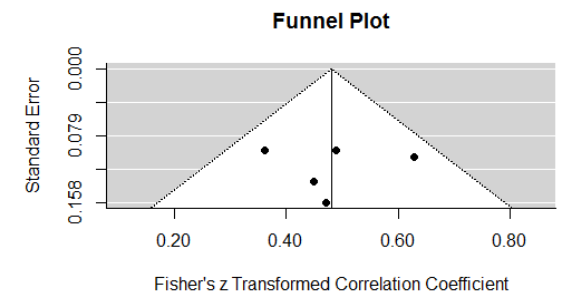


Figure 15. Psychological Distress and Emotional Representations

**Appendix 4.1** Interview guide (Study 3 and Study 4)

Interviewee Number and Codes:

Interviewer:

Introductory Information:

Introductions are made...

Information Sheet

Consent Forms

Before we get started I would like to ask you if you have any issues with the recording of today's interview. The recording of the interview is important so that all relevant information can be documented. After I have completed interviewing I will be transcribing the audio tapes into a written format. Please be advised that following this transcription all audio tapes will be destroyed and transcripts will be coded to preserve anonymity.

Interviewee Background and Demographics:

I would now like you to fill out this short questionnaire which asks you some general information about yourself and your illnesses.

There are some questions about your illness in the questionnaire that we might revisit later in the interview.

[NOTE: The indented questions are follow-up questions and don't need to be asked if participants already talked about this content]

Questions:

Can you tell me about your health?

Cancer Related Questions:

Could you please tell me about your cancer?

Perhaps you could start by telling me when and how you were diagnosed with cancer?

How did you feel when you first found out you had cancer?

Did being diagnosed and given the label of cancer help?

Could you describe/explain your cancer to me?

Do you feel you have a good understanding of cancer?

Does your illness 'make sense' to you?

Can you tell me about the symptoms of your cancer?

Do you have any thoughts about what may have caused your cancer?

What are these?

Do you perceive your cancer to be an acute (short-term), chronic (long-term), or cyclic (comes and goes) condition?

In the past and in the future

What do you perceive to be the consequences of your cancer?

How does cancer impact your life (every-day life)?

How has cancer changed your life?

Does it affect your career/relationships?

What can be done to help your cancer (if anything)?

How much control do you feel you have over your cancer?

How much control do you feel others have over your cancer?

How much worry or stress does your cancer cause you?

What do you do to treat your cancer? What treatment have you received in the past and what treatment are you currently receiving?

How much control do you feel your treatment has over your cancer?

How much control do you feel you have over your treatment?

How easy or difficult do you find it to adhere to your treatment regime and/or medication requirements?

What do you do to cope with your cancer?

What coping strategies do you use? (Practical? Social Support?)

Is there anything else you would like to tell me about your cancer?

Anxiety Related Questions:

Are you currently or have you ever been diagnosed or treated for anxiety?

When and how were you diagnosed with or treated for anxiety?

How did you feel when you first found out you had anxiety?

Did being diagnosed and given the label of anxiety help?

Could you describe/explain your anxiety to me?

Do you feel you have a good understanding of anxiety?

Does your illness 'make sense' to you?

Can you tell me about the symptoms of your anxiety?

Do you have any thoughts about what may have caused your anxiety?

What are these?

Do you perceive your anxiety to be an acute (short-term), chronic (long-term), or cyclic (comes and goes) condition?

In the past and in the future

What do you perceive to be the consequences of your anxiety?

How does anxiety impact your life (every-day life)?

How has anxiety changed your life?

Does it affect your career/relationships?

What can be done to help your anxiety (if anything)?

How much control do you feel you have over your anxiety?

How much control do you feel others have over your anxiety?

How much worry or stress does your anxiety cause you?

What do you do to treat your anxiety? What treatment have you received in the past and what treatment are you currently receiving?

How much control do you feel your treatment has over your anxiety?

How much control do you feel you have over your treatment?

How easy or difficult do you find it to adhere to your treatment regime and/or medication requirements?

What do you do to cope with your anxiety?

What coping strategies do you use? (Practical? Social Support?)

Is there anything else you would like to tell me about your anxiety?

Depression Related Questions:

Are you currently or have you ever been diagnosed or treated for depression?

When and how were you diagnosed with or treated for depression?

How did you feel when you first found out you had depression?

Did being diagnosed and given the label of depression help?

Could you describe/explain your depression to me?

Do you feel you have a good understanding of depression?

Does your illness 'make sense' to you?

Can you tell me about the symptoms of your depression?

Do you have any thoughts about what may have caused your depression?

What are these?

Do you perceive your depression to be an acute (short-term), chronic (long-term), or cyclic (comes and goes) condition?

In the past and in the future

What do you perceive to be the consequences of your depression?

How does depression impact your life (every-day life)?

How has depression changed your life?

Does it affect your career/relationships?

What can be done to help your depression (if anything)?

How much control do you feel you have over your depression?

How much control do you feel others have over your depression?

How much worry or stress does your depression cause you?

What do you do to treat your depression? What treatment have you received in the past and what treatment are you currently receiving?

How much control do you feel your treatment has over your depression?

How much control do you feel you have over your treatment?

How easy or difficult do you find it to adhere to your treatment regime and/or medication requirements?

What do you do to cope with your depression?

What coping strategies do you use? (Practical? Social Support?)

Is there anything else you would like to tell me about your depression?

Other Chronic Illness Related Questions:

Please tell me about any other health conditions you have

When was the condition diagnosed?

Are you receiving treatment for that condition?

What kind of treatment are you receiving?

What do you do to cope with these other illnesses?

What coping strategies do you use? (Practical? Social Support?)

Multimorbidity and Other Questions:

How have your thoughts about your health changed over time?

What is it like for you to have both cancer and anxiety?

Do you think one affects (or even caused) the other?

Does having both make things better or worse?

How does having both conditions affect your medication or treatment adherence?

Is one more challenging than another?

Would you prioritise one condition over another?

What is it like for you to have both cancer and depression?

Do you think one affects (or even caused) the other?

Does having both make things better or worse?

Is one more challenging than another?

Would you prioritise one condition over another?

What is it like for you to have cancer, anxiety and depression?

Do you think one affects (or even caused) the other?

Does having all three make things better or worse?

Is one more challenging than another?

Would you prioritise one condition over another?

What is it like for you to have a number of different health conditions?

Do they affect (or even cause) each other?

Does having multiple health conditions make things better or worse?

Is one more challenging than another?

Would you prioritise one condition over another?

Is there anything else you would like to tell me about?



**COREQ (Consolidated criteria for Reporting Qualitative research) Checklist**

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	82-83
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	83
Occupation	3	What was their occupation at the time of the study?	83
Gender	4	Was the researcher male or female?	83
Experience and training	5	What experience or training did the researcher have?	83
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	82
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	82
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	82
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	83
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	81
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	82
Sample size	12	How many participants were in the study?	84
Non-participation	13	How many people refused to participate or dropped out? Reasons?	84
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	83
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	83
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	84, Table 4.1, App 4.3
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	82, App 4.1
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	83
Field notes	20	Were field notes made during and/or after the interview or focus group?	83
Duration	21	What was the duration of the interviews or focus group?	83
Data saturation	22	Was data saturation discussed?	82
Transcripts returned	23	Were transcripts returned to participants for comment and/or	83

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	84
Description of the coding tree	25	Did authors provide a description of the coding tree?	84, 86, Figure 4.1
Derivation of themes	26	Were themes identified in advance or derived from the data?	83-84
Software	27	What software, if applicable, was used to manage the data?	83
Participant checking	28	Did participants provide feedback on the findings?	84
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	86, 88-96
Data and findings consistent	30	Was there consistency between the data presented and the findings?	86-103
Clarity of major themes	31	Were major themes clearly presented in the findings?	84, 86-96
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	86-96

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Appendix 4.3** Demographics and DASS-21 Stress subscale scores (Study 3)

Characteristic	Characteristic Sub-Categories	<i>N</i> (%)
Country of Birth	Australia	16 (76.2%)
	New Zealand	1 (4.8%)
	United Kingdom	4 (19.0%)
Education (highest level obtained)	Year 9 or Below	1 (4.8%)
	Year 10	2 (9.5%)
	Year 12	2 (9.5%)
	Certificate	5 (23.8%)
	Diploma	3 (14.3%)
	Undergraduate Degree	5 (23.8%)
	Post-Graduate Degree	3 (14.3%)
Employment Status	Paid Full-Time Work	2 (9.5%)
	Paid Part-Time Work	2 (9.5%)
	Paid Casual Work	2 (9.5%)
	Retired	6 (28.6%)
	Not Working Due to Health	6 (28.6%)
	Job Seeker	1 (4.8%)
	Other	2 (9.5%)
Relationship Status	Married	10 (47.6%)
	Divorced	1 (4.8%)
	Separated	1 (4.8%)
	De-facto Relationship	4 (19.0%)
	Single	5 (23.8%)
DASS-21 Subscale	Subscale Ratings	<i>N</i> (%)
Stress	Normal	4 (19.0%)
	Mild	0 (0.0%)
	Moderate	1 (4.8%)
	Severe	8 (38.1%)
	Extremely Severe	8 (38.1%)

## Appendix 5.1 Additional methodological information (Study 4)

*Information power* was used to determine the sample size for this study (Malterud, Siersma, Guassora, 2015). It provides clear criteria for ascertaining appropriate sample sizes in qualitative research while addressing some of the limitations associated with the use of *saturation* (Glaser & Strauss, 2009; Malterud et al., 2015). The sample size for this study was ascertained based on its neither especially broad nor narrow aims, the inclusion of participants specific to the research aim (based on meeting inclusion criteria), strong rapport and interview dialogue between ER and participants (due to a strong knowledge of the theoretical background and previous experience working with cancer patients), and the use of cross-case analysis.

Following recruitment and meeting of recruitment criteria, participants were invited to participate in the study. Participants were informed of the purpose of the study, as well as the researchers' reasons for completing it (to increase understanding of cancer patients' thoughts and experiences with a view to improving support service provision) at this early stage. Relationships were generally not established prior to study commencement, though six participants were known to the interviewer through support work with Cancer Council Tasmania. Field notes were not taken during interviews to maintain rapport and trust between interviewer and participant. Further, although participants were not offered a chance to review transcripts or provide feedback on identified themes, they were given an opportunity to request to be sent any research output or publications arising from the research.

## References

- Glaser, B. G., & Strauss, A. L. (2009). *The discovery of grounded theory: Strategies for qualitative research*. Aldine Transaction, New Brunswick, USA

Malterud, K., Siersma, V. D., & Guassora, A. D. (2015). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, 26, 1753-1760.  
doi: 10.1177/1049732315617444

**COREQ (Consolidated criteria for REporting Qualitative research) Checklist**

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	109
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	109
Occupation	3	What was their occupation at the time of the study?	109
Gender	4	Was the researcher male or female?	109
Experience and training	5	What experience or training did the researcher have?	109
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	App 5.1
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	App 5.1
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	109, App 5.1
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	109
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	108
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	108
Sample size	12	How many participants were in the study?	110-111
Non-participation	13	How many people refused to participate or dropped out? Reasons?	110-111
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	109
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	109
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	110-113, Table 5.2
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	108, App 4.1
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	109
Field notes	20	Were field notes made during and/or after the interview or focus group?	App 5.1
Duration	21	What was the duration of the interviews or focus group?	109
Data saturation	22	Was data saturation discussed?	108, App 5.1
Transcripts returned	23	Were transcripts returned to participants for comment and/or	App 5.1

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	109-110
Description of the coding tree	25	Did authors provide a description of the coding tree?	113-114, Figure 5.1
Derivation of themes	26	Were themes identified in advance or derived from the data?	109
Software	27	What software, if applicable, was used to manage the data?	109
Participant checking	28	Did participants provide feedback on the findings?	App 5.1
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	113, 115-117
Data and findings consistent	30	Was there consistency between the data presented and the findings?	113-121
Clarity of major themes	31	Were major themes clearly presented in the findings?	113-117
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	113, 115-117

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357